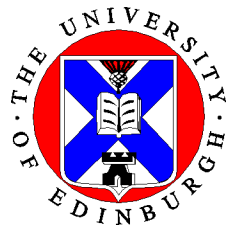


**“AGAIN”: AN ACCOUNT OF
DEMORALISATION IN PATIENTS AND
FAMILIES EXPERIENCING RECURRENCE OF
CANCER**

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ABSTRACT

AIMS The aims of this thesis are to provide understanding of the psychosocial impact of recurrent cancer on patients and family members and to develop a substantive theory that explains the phenomenon of recurrence from a psychosocial perspective.

BACKGROUND Cancer survival is increasing, and as people live longer, cancer recurrence is a real possibility. Recurrence has been described as one of the most stressful phases of cancer. Despite this reality, recurrence is poorly understood from a psychosocial perspective. Nurses, caring for patients and family members through their cancer trajectory, need to develop new understanding of how families experience recurrence in order to help them adapt to this phase of cancer.

METHODS This grounded theory study was conducted in four cancer units of two hospitals in North of Spain. The sample consisted of 15 patients, 13 relatives, and 14 nurses. Triangulation of sources of data including family interviews, individual interviews, memos, and literature was used to provide a different but complementary view of the impact of cancer recurrence. Data collection and analysis were based on the constant comparative method of grounded theory.

RESULTS A core category and three main categories have emerged from the data. The first main category, *“again”- when fear of recurrence becomes reality*, shows the suffering of cancer survivors and their family members after a diagnosis of recurrent cancer. The term *“again”* symbolises past suffering due to the fear of recurrence and new sufferings as a result of the diagnosis of recurrent cancer; it also implies a reencounter with health services and nurses. Suffering has been found to take on a social dimension in that recurrence was not an individual experience, but also a family experience. In addition, the social construction of suffering impacted on the nurses caring for the patients and families. The second main category, identified as *demoralisation as a response to the suffering of recurrence*, refers to the nature of suffering after the families knew that cancer had come back. Demoralisation has been found to be an emotional reaction characterised by feelings of exhaustion, uncertainty, and a resurgence of the fear of death. Such a condition posed great challenges to the nurses who described caring for these patients as harder than caring for newly diagnosed cancer patients. The third main category, identified as *rebuilding morale in the experience of recurrence*, highlights families’ search for meaning in their experience of recurrence and how nurses shifted the focus of care when caring for patients with recurrent cancer. The core category of this study is *demoralisation in cancer recurrence*. It is the foundation of a proposed theory for family nursing which explains what the experience of cancer recurrence involves for patients and families, and proposes a psychosocial framework for the management of demoralisation in families facing recurrent cancer.

CONCLUSIONS This thesis contributes to new understanding of the psychosocial impact of cancer recurrence on families and the nurses’ experiences of caring during the recurrent phase of cancer. The re-conceptualisation of demoralisation brings an original understanding of the concept, which has been unpublished and unexplored in cancer nursing so far.

DECLARATION

I hereby declare that this thesis has been composed by myself, this research is my own work, and that this work has not been submitted for any other degree or professional qualification.

Cristina G. Vivar

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CHAPTER 1

OVERVIEW OF THE STUDY

Introduction

This chapter outlines the context, research justification, and aims of this study. A discussion of the personal, practical, and academic significance for conducting this thesis is provided. Key concepts used in this study are also defined. Finally, an overview of the organisation of this work is briefly discussed.

Context of the study

Cancer is a public health problem of wide magnitude in western countries in terms of incidence and mortality (Boyle & Ferlay 2005, Jemal *et al.* 2005). In Spain, where this research was conducted, as well as in other European countries, cancer is the second cause of mortality (Arrázola & Gabilondo 2001). Given that epidemiological situation, the improvement of cancer services across Spain has been a priority on the political agenda in recent years. The Spanish Department of Health passed a programme in 2003, named *Plan Integral contra el Cancer* (Integral Plan against Cancer), that aimed to reduce the incidence and mortality due to cancer through prevention and early detection as well as improvement and equality of healthcare delivery across all Spanish Communities (Matey 2003, Perancho 2003).

In Navarra, one of the seventeen Spanish Communities and where the current study was based, earlier priority to establish a strategic cancer programme was given because in that region cancer was the first cause of death in men and the second cause of death in women (Ardanaz-Aicua *et al.* 2001). An oncology programme

named *Plan Oncológico de Navarra (Oncological Plan of Navarra)*, was therefore signed in June 2001 for the period 2001-2005 to enhance cancer healthcare services across Navarra (Gobierno de Navarra 2001). Among others, two of the health priorities of this programme were to reduce cancer mortality rates and to promote a health system of quality for patients with cancer and their families. A multidisciplinary attention was thus considered in order to achieve holistic care in the context of cancer (Departamento de Salud 2002). As a Social Science discipline, nursing plays an important role in the multidisciplinary team, providing physical and psychological care for cancer patients and their family members and contributing to the integral and individualised care of people (Ferrell *et al.* 2003). Research to reduce mortality and increase cancer survival has been a priority in cancer services (Arrázola & Gabilondo 2001), and in addition, nursing is interested in investigating how to improve cancer care (Browne *et al.* 2002, Ropka *et al.* 2002).

In Europe, there is ever-increasing interest in investigating aspects related to the experiences of cancer patients and their families. The areas of diagnosis, treatment, survival, as well as the terminal phase of cancer in particular have received greater attention in nursing research (Reuben 2004a). Little is known, however, about the recurrent phase of cancer. According to a report commissioned by The National Cancer Policy Board and Institute of Medicine, there is a “lack of content on critical areas, including the prevention of secondary cancers, treatment of recurrent cancer, and rehabilitative services” (Ferrell *et al.* 2003, p. E5). Cancer nurse researchers, besides investigating phenomena of continuing concern, such as pain management, should explore areas of emerging interest such as cancer recurrence management (Ropka *et al.* 2002). Considering that nursing is interested in the cancer trajectory of people affected by the illness, understanding how the experience of cancer recurrence affects people within a particular context will add to an understanding of the experiences of living with cancer.

Statement of the problem

Cancer survival is increasing, so that more patients with cancer live longer, increasing the number of survivors (Jemal *et al.* 2004). This fact contributes in turn to the possibility of increases in cancer recurrence (Gotay & Muraoka 1998). Given recurrence is likely to occur when first diagnosis of cancer has happened, the expectation would be that considerations of the meaning of recurrence within the nursing literature would be numerous, but this has not been so. There is great evidence about how fear of recurrence is a stressful event for cancer survivors and their family members (Black & White 2005, Lee-Jones *et al.* 1997). Few studies, however, have sought to investigate their perceptions once recurrence has been diagnosed (Oh *et al.* 2004, Ullrich *et al.* 2003). It is important to explore changes that occurred when moving from survivorship to a diagnosis of recurrent cancer because recurrence has been said to be more stressful than other cancer stages (Frost *et al.* 2000, McEvoy & McCorkle 1990, Weisman & Worden 1986); even more than the initial diagnosis (Lewis & Deal 1995, Mahon *et al.* 1990).

Only a few studies have considered the impact of a cancer recurrence among cancer survivors (Mellon *et al.* 2006, Oh *et al.* 2004). This means that the phenomenon of recurrence is poorly known from a psychosocial perspective; in contrast to the increasing attention received about the biomedical perspective of recurrent cancer (Shen *et al.* 2005, Touboul *et al.* 1999). Although it is important to recognise the medical aspects of recurrent cancers, understanding the *experience* of the phenomenon is of similar importance when caring for individuals long-term. Psycho-oncology research in this area is therefore required. Besides, few studies have looked at the impact of cancer recurrence from the patients' and family members' perspectives. However, there is evidence that cancer recurrence affects the whole family unit (Halliburton *et al.* 1992).

Surprisingly, even though research has revealed that caring for cancer patients is emotionally challenging for nurses (Kruijver *et al.* 2001), notably during the terminal phase of cancer (Kuuppelomaki 2003, Skilbeck & Payne 2003), no study has been

undertaken to specifically examine how nurses working in cancer services conceptualise caring during the recurrent phase of cancer. It would be reasonable for nurses to give their own views on their experiences in relation to caring for people during this phase of the illness trajectory. This is because nurses, who are involved in the care of the patients and their family members, contribute to or add some elements to the experience of cancer.

Considering that the study of cancer recurrence has been framed mainly within a medical and patient-centred research paradigm and that there is lack of evidence on the experiences of nurses who care for these patients, increased attention in investigating the psychosocial experiences of cancer recurrence is needed. Understanding how cancer recurrence impacts on the patients and their family members and how nurses conceptualise caring during the recurrent phase of cancer will add to an understanding of the psychosocial meaning of the phenomenon of cancer recurrence.

Purpose of the study

Patients with recurrent cancer and their family members have to deal with physical and psychosocial effects due to the reappearance of cancer. Recognising both physical and emotional consequences of a cancer recurrence is central to all care. However, management of physical aspects of cancer is often the major goal of health carers in detriment of psychosocial aspects of cancer (Willard & Luker 2005). In this thesis, the focus is on the emotional impact of a cancer recurrence as perceived by patients with recurrent cancer, their families, and nurses caring for them in hospital. The reason for including nurses in this research is to identify their experiences of caring for families during cancer recurrence rather than to assess the adequacy of the nurses' accounts of their care. In addition, exploring the experiences of these three groups of participants will elucidate an understanding of the phenomenon of recurrence from the perspectives of the "therapeutic triangle in healthcare" (Hanson & Boyd, 1996).

This study was designed to contribute to knowledge of the experience of cancer recurrence from the perspectives of patients, family members, and nurses in hospital units. It sought to discover and provide an understanding of the meaning of cancer recurrence from a Spanish social context using grounded theory. In order to achieve the above purpose, the aims of this qualitative study were:

General aims:

- To provide understanding of the psychosocial impact of a recurrence of cancer.
- To generate a substantive theory that described the experience of cancer recurrence from a psychosocial perspective within the Spanish context of healthcare services.

Specific aims:

- To describe patients' and family members' experience of a cancer recurrence.
- To describe nurses' experience of caring for patients with recurrent cancer and their family members.
- To report the major challenges, issues, and problems patients and their family members have faced from the moment the recurrent cancer was diagnosed.
- To find out what support patients and family members would like to receive from nurses during treatment for recurrent cancer.

Justification for the thesis

Personal, practical, and academic support for the study and its significance for improving the quality of cancer practice are briefly presented next.

PERSONAL INTEREST

My interest in families living with recurrent cancer began in early 1998, when I worked in a cancer inpatient setting and cared for patients and family members during the treatment, recurrence, and terminal phases of cancer. I often felt that nurses, including myself, were uncomfortable when caring for patients and family members in these sensitive situations. This role posed difficulties because little preparation was offered about how to deal with the psychosocial needs of both patients and family members, and how to support them in the different phases of cancer. At that time, I was myself a family member of a cancer survivor. I became then keenly interested in understanding how people lived with cancer and the factors that seemed to influence their emotional response to the disease. The pursuit of this interest led me to a master dissertation in the area of psychosocial experience of long-term cancer survivors. A year later, I experienced the “bump” of recurrence as my relative was diagnosed with recurrent cancer. This event added a personal dimension to my interest in families living with a recurrence and pushed me to define the focus of this research.

SIGNIFICANCE FOR CANCER PRACTICE

The purpose of nursing is to help individuals cope with the experience of illness and suffering, and if possible, to alleviate their suffering (Travelbee 1971). In the cancer trajectory, the event of a recurrence is a distressing situation which requires support from healthcare professionals, a support not always offered (Bull *et al.* 1999, Eriksson & Lauri 2000, Foy & Rose 2001, Frost *et al.* 2000, Northouse *et al.* 2002a). The results of this study will provide nurses and other health professionals with a deeper understanding of the experience of cancer recurrence as interpreted by patients with a recurrent cancer and their family members. Quality of care may be enhanced for these families as the oncology team acknowledges management of the psychosocial aspects of cancer recurrence.

Particularly, there is a lack of understanding of the phenomenon of cancer recurrence from different cultures. Most of the available literature about the experience of cancer in families has focused on British, Canadian, and American families. Although the aim of this study was not to compare families' experiences depending on their cultures, this research will bring new data regarding the experiences of Spanish families about cancer recurrence. This knowledge is important as it has been recognised that the different views, expectations, and beliefs regarding cancer shapes people's behaviours toward the illness (Ashing-Giwa *et al.* 1999). Therefore, understanding more about the experiences of Spanish families in relation to cancer recurrence and about their perceptions of the support they require from professionals during treatment is necessary. Such information will hopefully help nurses and health professionals to plan adequate psychosocial interventions in an attempt to manage the emotional concerns of families during a recurrence of cancer.

Findings from this research may provide the foundation for a research program specific to families living with a recurrence of the illness and may guide future investigation in relation to assessment instruments and psychosocial interventions to help families deal with a recurrence of cancer.

ACADEMIC INTEREST

In Spain, most cancer research has been conducted and published from the perspective of physicians. Nursing, though also responsible for the provision of care to cancer patients and their family members, has not paid sufficient attention to the study of the experiences of individuals facing recurrence. Surprisingly, no study has been found in the Spanish nursing literature that presents an understanding of the feelings, thoughts, and experiences of families facing a cancer recurrence. The present research, therefore, focuses on cancer care from a nursing perspective.

In addition, most of the tools that are used in nursing practice are generated in the United States or in different European countries (Myers 2004). However, it is

important that Spanish nursing produces its specific and contextual knowledge within its own culture and traditions. This will generate a specific body of knowledge that may respond to the needs of individuals, families, and the community within the Spanish family context.

A good reason for investigating the impact of recurrent cancer is also given by limited evidence on qualitative experiences of individuals facing a recurrence. This study will provide a means of understanding the qualitative experience of facing a recurrence of cancer as perceived by the participants.

A final academic interest relates to theoretical development. Theories in Social Sciences define what a particular illness is, how to prevent it, in what sense the illness affects individuals, or what the care needs are at the different stages of the illness (Meleis 1997). Nursing still lacks knowledge to define these models regarding specific circumstances such as a recurrent cancer. Then individuals experiencing a recurrence do not always have answers to questions that this situation may pose. The development of a substantive theory that explains the psychosocial nature of recurrence will provide answers to some of these questions.

Key concepts

A word or concept can have different meanings for different individuals and even for different cultures. Subsequently, a word may have different implications in practice depending on its meaning for a particular population. Clarifying the most important concepts in a piece of research can help understanding terms in the context of the research, facilitate reading of a manuscript, and most importantly, avoid misinterpretations of the findings of a study. Five of the most frequently used terms in this research that can be misunderstood are defined below. Others concepts are defined in Appendix 1.

CANCER RECURRENCE

According to Mahon and Casperson (1997), cancer recurrence is “the clinical state in which a person with cancer who has successfully completed an initial course of therapy and has been without signs and symptoms of clinical disease for a period of at least 6 months is found to again have evidence of malignancy” (p. 180). In other words, recurrence occurs when cancer comes back (recurs) after it has been treated. A cancer recurrence is then the reappearance of cancer. Cancer may come back in the original place or in another part of the body (National Cancer Institute 1990). A concept analysis of cancer recurrence will be presented in the literature review.

Cancer recurrence is commonly divided into three categories, namely local, regional, and distant. Local recurrence refers to a reappearance of illness in the same place it was first found. Regional recurrence refers to the spread of malignant cells to tissue located close to the original cancer. Distant recurrence refers to cancer that has spread or metastasised to tissues farther away from where the first cancer was located (Touboul *et al.* 1999). This study considers the discovery of metastases as a recurrence of cancer. This is because the interest of this research is in individuals who are dealing with a *repeated experience* of cancer and not about the parts of the body where metastases have spread. The focus of this study is on *time and experience* rather than on *place and disease*.

The terms recurrent cancer, cancer recurrence, relapse, second malignancy, and second neoplasm are used interchangeably in this thesis to refer to the return of the disease.

PATIENT WITH RECURRENT CANCER

In this study, a patient with a recurrent cancer is a person who is diagnosed with cancer after s/he has survived for a period of at least 6 months without evidence of the disease and who is receiving treatment, which in principle is not palliative.

Besides, the person has a life expectancy of more than 6 months at the time of the diagnosis of recurrent cancer.

CANCER SURVIVOR

A cancer survivor is a person who has survived cancer after completion of treatment and who may experience physical, psychosocial, and spiritual sequelae due to cancer and side effects of treatment (Vivar & McQueen 2005). A short-term cancer survivor generally is defined as the person who has lived from cancer diagnosis up to five years without evidence of the disease. A person who has lived for over five years from cancer diagnosis without recurrence is identified as a long-term cancer survivor.

FAMILY

Given the variety of views regarding the concept of family, it is difficult to build a universal definition of family. However, clarifying the meaning of the family within this research is important since the definition influences the entire research process (Ästedt-Kurki *et al.* 2001). This will enable readers to better comprehend the aim and findings of the research, and anticipating potential misunderstandings.

The Family Nursing Network (FNN), a Scottish initiative to support the use of family nursing in practice, research, and education offers the following definition (Claveirole *et al.* 2001):

The family consists of two or more individuals joined by affectional bonds, the influence of which may fluctuate with time and circumstances but which persist through the lifespan. Family membership is mutually defined and includes elements of shared beliefs, emotional, social, physical, and economic support (p. 1142).

The above definition includes essential aspects of the family, such as its dynamic structure and the family as a unity of shared values. It also emphasises the fact that the family is defined by its family members. Incorporating central notions of the above definition and others definitions in the literature (Hanson *et al.* 2005), family in this study refers to the social unit that is composed of a patient and his/her close family members who are joined together by emotional bonds and who identified themselves to be part of the family. In this context, a family member, also referred to in this work as a relative, loved one or a significant other, is a member of the family who accompanies the patient through the cancer trajectory and who is mutually identified by the patient and by himself as a family member.

EXPERIENCE

Experience is “what a person feels like when something happens” (Entwistle *et al.* 2002, p. 232). Experiences are concerned with beliefs, meanings, feelings, and expectations. Though this research seeks to understand the common experience of individuals regarding a cancer recurrence, it is anticipated that this can only be possible if one understands that *every person* is unique, and that her experience is individual. Within this exclusive experience, however, each personal experience is co-made by a relationship with others and the world. This perspective is also supported by the theory of symbolic interactionism, which I shall explain in the research methodology of this study.

Organisation of the thesis

This thesis is divided into eight chapters which aim to contribute to new understanding of the psychosocial phenomenon of cancer recurrence. The current chapter introduces the context of this research to allow readers to have an overview of this work. Chapter 2 presents background literature about physical, emotional, and social aspects of cancer recurrence and it further supports the research aims and

research methodology. Chapter 3 refers to the design of this study, which adopts an interpretative design framed within the qualitative paradigm. The foundations of grounded theory guide the research process. Chapter 4, 5, and 6 describe the major findings of the study. Chapter 7 presents the original intent of this work, that is, to develop a substantive theory about the phenomenon of cancer recurrence from a psychosocial perspective. Finally, Chapter 8 discusses the contribution of this study in terms of academic, empirical, and personal implications. Limitations of the study and recommendations for future research are also discussed.

Summary

This chapter demonstrates why this research problem warrants research attention. The next chapter presents the background literature that further confirms support for the research aims and research methodology of this work.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

In grounded theory, the aim of a review of the literature before the research proposal is to provide a rationale for the potential contribution of the study, and to show that no identical research has been conducted in the field (Glaser & Strauss 1967). While collecting and analysing the data, the grounded theorist should conduct an exhaustive review of the literature with the aim of testing the categories that emerge from the data (Charmaz 2006). In accordance with grounded theory, I initially conducted a brief review to ensure that my research proposal was original. During the collection and analysis of the data, as well as during the writing up of this thesis, I conducted an ongoing literature review that helped me to test the emerging categories by comparing them with existing research (as I shall describe in chapter 3).

The present chapter reviews contemporary issues pertaining to cancer statistics, especially related to cancer recurrence, psycho-oncology, and family nursing care. The interest of this research is in the experience of recurrence rather than the disease of cancer itself. However, to understand experiences of illnesses, it is important to understand processes of diseases. Therefore, the first part of this chapter examines the epidemiology of recurrent cancer with a focus on cancer survival and the factors associated with the risk of recurrent cancer. Following this, a concept analysis of cancer recurrence is provided with the intention of clarifying the inconsistent description of the concept within literature. Then, the different phases of the cancer trajectory are described, and specific research on the psychosocial impact of cancer recurrence in adult patients and family members reviewed (research on paediatric cancer is not dealt with in this study). Lastly, attention is given to nursing approaches

to family suffering and ways to recognise suffering in cancer patients and family members. Issues related to family nursing in cancer care are briefly discussed.

This review could have examined different topics, such as psychological coping in patients with cancer and their family members. However, the many ways of coping with cancer have been studied and documented more extensively than the impact of cancer on the lives of patients and family members at different phases in the cancer trajectory, and especially during the recurrent phase. Therefore, this review focuses on the abovementioned topics with the intention of developing an original examination of the literature.

Epidemiology of recurrent cancer

Measuring the burden of cancer is a topic of perennial interest to public health researchers and policy makers because of the high incidence and mortality of the disease (Boyle & Ferlay 2005). Measures of incidence, prevalence, and mortality are used to describe the general state of cancer in the population and to establish public health goals (Schottenfeld & Beebe-Dimmer 2005). Among these goals, one of much interest for government policy, including the Spanish Government of Navarra where this study is based, is the decrease of mortality and increase of survival (Gobierno de Navarra 2001). This may be because cancer survival is considered as an indicator of the overall effectiveness of the health care system (Berrino *et al.* 1999, Berrino *et al.* 1995). Although such measures have been the most frequently used indicators of cancer state, there is also increasing interest in designating measures that assess health quality of life in cancer (Brown *et al.* 2001).

“Population-based figures give us survival estimates for various cancers, but those figures do not speak to the individual patient whose experience is unique and not determined or described by aggregate data” (Mullan 1985, p. 271). In agreement with Mullan, cancer is not a disease based on statistics only but is an illness experienced by persons. Therefore, research on the biomedical advances of cancer together with

the psychosocial experience of the illness should be a priority for researchers and policy makers. The priority of this section is to examine current data on the state of cancer survival in Europe to evidence the importance of continued investigation about issues of survival and patterns of cancer recurrence. Later sections will present psychosocial aspects of the different stages of cancer, with a focus on cancer recurrence.

CANCER SURVIVAL

Cancer survival may be defined as the time from diagnosis of cancer to death (Moreno-Iribas & Ardanaz-Aicua 2004). The increase in screening tests for detection of early stage cancer has apparently beneficial effects on cancer survival. Prostate cancer screening is beneficial because mortality from this type of cancer has decreased and is associated with the introduction of advanced techniques for detecting early prostate cancer (Potosky *et al.* 1995). Similarly, screening for colorectal cancer has been shown to be effective (Boyle *et al.* 2003). The introduction of mass mammography screening programmes is also said to be successful in reducing mortality from breast cancer in Europe (Boyle & Ferlay 2005). However, breast cancer screening has been under debate after two Danish researchers concluded that screening for breast cancer with mammography was unjustified, as there was no reliable evidence that mammography screening reduces mortality (Gotzsche & Olsen 2000). Such affirmation opened an international debate, which has been summarised in a Spanish nursing paper (Vivar 2005a). Now, this debate seems to be solved in support of the effectiveness of breast cancer screening to reduce mortality (Perancho 2003). Leaving this debate aside, health is an intrinsically holistic concept, and it cannot be reduced to simple measures of morbidity and mortality. Therefore, as well as continuing investigating to improve screening tests, interest should be also directed to improving care for women when attending distressing mammography clinics (Vivar 2005b).

In addition to advances in cancer screening, significant progress has been made in the development of more effective cancer treatment (Palmieri & Perez 2003). This has led to decreases in cancer mortality, accompanied by increasing cancer survival internationally (Jemal *et al.* 2004, Jemal *et al.* 2005, Sant *et al.* 2001). Clearly, other factors such as age at diagnosis, type of cancer, stage at diagnosis, and access to healthcare facilities have influenced survival estimates (Micheli *et al.* 2003, Sant *et al.* 2003, Schroevers *et al.* 2004).

Given that cancer continues to be a worldwide problem, registers have been developed providing regular monitoring of cancer state internationally. For example, the National Cancer Institute (NCI) and the North American Association of Central Cancer Registries (NAAACCR) provide updated information regarding cancer incidence and trends in the United States. At a European level, the International Agency for Research on Cancer (IARC) and the European Network of Cancer Registries (ENCR) provide regular information on the estimates of the incidence and mortality from cancer across European countries. In the light of increasing cancer survival, the EURO CARE project (European Cancer Registry-based Study on Survival and Care of Cancer Patients) was established in 1989 to measure and explain international differences in cancer survival in Europe. Since then, three reports have been published monitoring cancer patient survival across the European population from 1978 to 1999 (Berrino *et al.* 1999, Berrino *et al.* 1995, Sant *et al.* 2003).

The main findings from this European project, based on the follow-up of European cancer patients, show an increase of the average 5-year survival rate over time for most cancers, although differences in survival rates continue between European countries. The overall increase in breast cancer survival has been found similar to that for colorectal cancer, thus indicating that screening programmes seem to be effective in reducing mortality from cancer, as discussed earlier. Besides, survival for all tumours was better in young than old patients and better in women than men. Therefore, survival is increasing for most cancers and in most European countries, but differences remain between age groups, gender, and European countries

(Coleman *et al.* 2003). In Spain, and particularly in Navarra, the overall cancer survival has also improved (Moreno-Iribas & Ardanaz-Aicua 2004).

The above data instil a sense of hope and optimism in relation to cancer survivorship. Parallel to the increase of cancer survival in Europe (Reuben 2004a) and in the United States (Reuben 2004b), the prognosis of many cancers has improved. This pattern suggests that the course of cancer has changed from acute terminal illness to chronic disease (Polinsky 1994). An improved 5-year survival rate for individuals diagnosed at an early stage of disease is increasing, resulting in larger number of long-term cancer survivors (Reuben 2004a, Sporn 1996). There is evidence that the issues of living with and beyond cancer are common, and this gives raise to important concerns about the need to meet the challenges of cancer survivors. Among these challenges, one of major priorities is to alleviate suffering from cancer and help families deal with the fear of recurrence which generally implies a sense of alertness, even long-term after the end of cancer treatment (Reuben 2004b). This is because as cancer survival increases, and people live longer, the possibility of recurrence also increases.

RISK FACTORS ASSOCIATED WITH RECURRENCE

Data on the incidence of recurrent cancer are scarce. Indeed, it is surprising to find that statistics on trends in cancer incidence and mortality rates, 5-year cancer survival rates, and even expected numbers of new cancer cases are available to the detriment of data about the estimates of recurrent cancer and incidence of recurrence for prevalent cancers. However, changes in cancer-specific survival rates after diagnosis may be accompanied by increases in recurrence rates, meaning that the prevalence of risk factors of recurrence may influence survival rates. The possibility of developing recurrence is multi-causal and therefore, depends on different determinants including type of primary tumour, stage at diagnosis, cancer treatment, age at diagnosis, social support, and psychological states. Although information on these determinants is

limited, and most of these studies focus on breast cancer, the aim of the next section is to present the evidence available on this matter.

Prognostic factors such as the type of primary cancer itself and the cancer site have a major influence on the probability of developing recurrence (Shen *et al.* 2005). For instance, it is commonly known that breast cancer generally has better prognosis than pancreatic cancer. In addition, the duration of disease-free interval has been reported as significant for survival. It has been argued that most recurrences occur before the 5-year survival period after the end of treatment (Gotay & Muraoka 1998). Therefore, a long duration of disease-free interval is associated with better prognosis. Concerning cancer treatment, receiving combined therapy (e.g. surgery and radiation) seems significant to improve control of cancer (Touboul *et al.* 1999, Vargas *et al.* 2005).

The stage of the carcinoma at diagnosis undoubtedly plays a significant role. For most tumour sites it is usually accepted that stages I and II are considered as early-stage cancer in contrast to stages III and IV that are referred to as being advanced-stage cancer. In this view, patients with advanced cancer are more likely to have a poor prognosis compared with patients with loco-regional recurrence early-stage cancer. Besides, patients with lymph node involvement at primary diagnosis have poorer prognosis compared with patients without node involvement (Rack *et al.* 2003). Patients with more than two factors including positive lymph node metastasis and a young age showed a poor 5-year local-relapse-free survival rate (Kim *et al.* 2005). Besides, age at diagnosis seems to influence the possibility of recurrence. The lifetime probability of developing recurrence is higher for individuals younger than 45 years old (Vargas *et al.* 2005). In a retrospective cohort analysis performed on 1,267 patients with loco-regional breast cancer, the authors found that older women ($65 \geq$ years old) experienced a longer disease-free interval before recurrence and overall longer survival than younger counterparts (Lyman *et al.* 1996). Yet, the authors concluded that prognosis should be based on disease stage and histological parameters rather than age.

A growing body of knowledge suggests that there is direct relationship between psychological states and survival. Some argue that a person's cognitive attitude and emotional response to a diagnosis of cancer can influence survival (Watson *et al.* 1999). Others conclude that chronic stress after a diagnosis of breast cancer appears to be strong predictor of early relapse (De Brabander & Gerits 1999). A more recent research has supported that depressive symptoms have a negative influence on long-term cancer survival (Brown *et al.* 2003). Interest in the association between coping and length of survival is so great that cancer patients are aware of this fact, and they may believe that if they do not have a positive attitude their cancer will spread. This is what Holland and Lewis have named "the tyranny of positive thinking" (Holland & Lewis 2001). However, research is inconclusive on the association between psychological states and survival. A systematic review has supported that there is little convincing evidence that psychological coping styles have a clinical effect on survival from cancer or recurrence of the disease (Petticrew *et al.* 2002). Methodological problems such as failure to control important medical and demographic factors, small sample sizes, and the samples restricted to advanced-stage patients have contributed to the uncertainty of the role of psychological state in long-term cancer survival (De Boer *et al.* 1999).

The reviewed studies on prognostic factors and risk of recurrence provide evidence of current patterns of cancer recurrence. The evidence suggests that the risk of recurrence in patients depends on multiple predictors. Common prognostic factors include stage, nodal involvement, tumour size, age, and coping style. Based on these results, the extent to which these predictors contribute to the probability of recurrence should be interpreted cautiously. Assessment of the risk of recurrence should be based on individual patient prognostic factor rather than general information. However, the information presented above will certainly help professionals to inform patients and families about the risk factors of recurrence, and will contribute to reduce the unnecessary level of fear when prognosis is good and the possibility of recurrence is minimal. Families with a high risk of experiencing recurrent disease may be helped by preparing them psychologically in advance and empowering them to have a better sense of control. Finally, the evidence on the

epidemiology of recurrent cancer gives reasons for continuing efforts to reduce the statistical and psychological burden associated with cancer recurrence.

Before examining the psychological issues of recurrence, it is central to understand the concept of cancer recurrence by analysing its meaning and use within literature.

Cancer recurrence: a concept analysis

This section is not intended to be a systematic analysis of the concept of cancer recurrence but to show the necessity of clarifying the meaning of a concept in published work. Talking about concepts helps to bring them into conscious thought and lessens the risk using them unthinkingly (Kitson 1993). Concept analysis offers a means for discovering definitions and meanings of a concept, explains why these meanings have emerged, and identifies common usage of the concept and its applicability in different scientific contexts (Rodgers 1993a). Rodgers' evolutionary model describes the steps in the process of concept analysis, beginning with selecting a concept, reviewing the literature, collecting and managing the data, and finally interpreting the data and writing up the findings (Rodgers 1993b). This theoretical model was considered to explore the meaning of recurrence and its applicability in cancer care.

For this purpose, an electronic search was undertaken using different health-related databases, including Cinahl, Medline, Cancerlit, Embase, and Pubmed from 1985 to August 2006. To limit the search to the concept under study specifically, I searched for publications that contained the following combination of terms in their title: "cancer recurrence", "recurrent cancer", "recurrence and cancer" or "recurrence". All the articles that contained at least one of the above terms in their title were selected and their abstract read. Those papers considered to be of interest for this study were selected. Hand searching was also conducted on all collected articles for additional studies.

Although the concept of recurrence has been used in the medical and nursing literature, including cardiology and psychiatry (Bocking *et al.* 2006, Yager *et al.* 2005), most of the papers are based on cancer, in particular in the medical management of recurrent cancers and the psychosocial dimension of recurrence of cancer. Many of these papers were reviewed but only those considered most significant for this study have been chosen and are referred to below.

DEFINITIONS OF CANCER RECURRENCE EMERGING FROM THE LITERATURE

Generally speaking, recurrence is an event that recurs, an event happening anew. Most of us experience recurrent incidents, such as recurrent dreams. In this universal view, Rawnsley (1994) has defined recurrence as follows:

the return or reappearance of a phenomenon; to recur means to happen again after an interval, to come up again for consideration (p. 343).

According to the Dorland's Medical Dictionary, recurrence comes from the Latin words *re-* meaning again. Recurrence is then "the return of symptoms after a remission" (Dorland's Illustrated Medical Dictionary 1965, p.1297) The adjective "recurrent" comes from the Latin word *recurrens* meaning returning, and is defined as "running back or toward the source" and "returning after intermissions"(Dorland's Illustrated Medical Dictionary 1965). Intermission is "an interval: a period of temporary cessation, as between two occurrences or paroxysms" (p. 749). Paroxysm is "a sudden recurrence or intensification of symptoms" (p. 1104). Using similar central notions from the above dictionary definitions, an information booklet for patients whose cancer has recurred defines a cancer recurrence as:

the reappearance of disease that was thought to be cured or inactive (in remission). Cancer may recur after several weeks, several months, a few years, or many years (National Cancer Institute 1997, p. 3).

Incorporating aspects of disease-free interval, Mahon and Casperson (1997) defined recurrent cancer as:

The clinical state in which a person with cancer who has successfully completed an initial course of therapy and has been without signs and symptoms of clinical disease for a period of at least 6 months is found to again have evidence of malignancy (p. 180).

In addition, recurrence is distinguished from new, second cancer in that “a recurrence has the same type of cancer cells as the original tumour, no matter where it is found” (National Cancer Institute 1997, p. 3). This point is important because the options of treatment differ (as will be discussed later). Recurrent cancer can be in an area close, regional, or distantly located relative to the primary tumour site. Depending on the location, recurrent cancers are classified as local, regional, and distant recurrence (National Cancer Institute 1997, p. 4). Local recurrence is when malignant cells develop in a place close to where a first cancer was found; in this case, there is no sign of lymph node involvement. Regional recurrence is when cells develop around the area where the first cancer grew; lymph node involvement occurs but there is no evidence of dissemination of cancer in the body. Finally, distant recurrence is when cells spread to other parts of the body, also called metastatic recurrence.

Typically, medical papers define recurrence that is specific to a type of cancer. For example, breast cancer recurrence has been defined in terms of the discovery of metastasis (Andersen *et al.* 2005):

the clinical detection of metastatic breast disease in the same area, adjacent to, or distant from the original site (p. 1542).

Certainly, health professionals should acknowledge the biomedical stage of cancer if medical management is to be effective. However, professionals should also identify the psychosocial experience of the event because recurrence has been identified as a “crisis of courage” which requires intrapersonal and interpersonal resources in an attempt to move on to another state, which is always uncertain (Rawnsley 1994).

The conclusion stemming from the analysis of the concept of cancer recurrence is that the variety of definitions depending on backgrounds limits to some extent universal understanding of the concept of recurrence. When research is medical-based, authors generally refer to recurrent cancer. This may be because the focus is on the *disease* of cancer. However, from a nursing perspective, there is a tendency to refer to cancer recurrence as comprising the experience of disease. Accordingly, the concept of cancer recurrence refers commonly to the *experience* of the return of cancer whereas the terms recurrent cancer refers to the physiological characteristics of the disease (stage, type of tumour cells). While recurrent cancer resides within a disease-relapse view and is defined biomedically, recurrence focuses on the illness-relapse and is associated with both physical and psychological dimensions.

SURROGATE AND RELATED TERMS

The exploration of the literature shows other terms used as synonymous with cancer recurrence. These are: recurrent cancer (Weisman & Worden 1986), relapse (Simonelli 2005), second malignancy, second neoplasm, second cancer (Thornton *et al.* 2005), spread of cancer, disseminated disease (McEvoy & McCorkle 1990), advanced disease, return of cancer and metastatic cancer (Okamura *et al.* 2000). The wide number of terms referring to cancer recurrence shows the lack of homogeneity in the medical terminology. All the above terms are used interchangeably to refer to cancer recurrence, preventing readers from differentiating characteristics of different types of tumours and different stages of cancer. This great variation, even among people with the same type of recurrence, presents a genuine challenge to any attempt to describe the experience of recurrence from the literature.

ATTRIBUTES OF CANCER RECURRENCE

Aside from the different definitions encountered within literature about the concept of recurrence, there appears to be agreement across literature that the characteristic of

repetition is central to recurrence. In addition, the majority of experts hold the view that recurrence of cancer requires new medical and psychological management, as well as social management pertaining to financial, work, family, and social life management. By cancer recurrence, therefore, we mean not just the physical course of illness but all the psychological and social consequences that encircle the course of cancer.

This section has not intended to be conclusive about the meaning of recurrence but to provide a catalyst for further consideration in practice and research. As said earlier, researchers should indicate their meaning of cancer recurrence to enable readers to interpret the characteristics of the population being studied adequately. While there is certainly no universal agreement on the definition of the concept, there is evidence to suggest that recurrence is part of the cancer trajectory, as we shall see next.

The cancer trajectory

Reactions to cancer and its treatment must be seen as related events which proceed from the first perception of a sign of illness, to the culmination of hospitalisation and treatment, and then to the convalescence and cure, recurrence, or dissemination and death. In the present study, I consider the cancer trajectory, not to focus on every stage of cancer, but rather to contextualise cancer recurrence. This is because any emotional response in the sequence can only be understood in terms of emotional responses earlier in the sequence. By increasing awareness of the cancer trajectory, we will be better prepared to identify patients', families', and professionals' needs along a continuum of cancer, in which recurrence is an integral part of the cancer trajectory.

The next two sections present respectively an understanding of cancer viewed as a chronic illness and the characteristics of the Chronic Illness Trajectory Framework.

UNDERSTANDING CANCER AS A CHRONIC ILLNESS

Lubkin and Larsen (2002, p. 3-4) recommend differentiating between disease and illness as both terms are used interchangeably by healthcare professionals, resulting in a lack of accuracy of the medical jargon. *Disease* concerns an alteration in the anatomy and functioning of a part of the body whereas *illness* refers to the experience of individuals' physical and psychological suffering. The interest of the current research is in the experience of the illness rather than the disease itself. Yet, to understand illnesses we should also know essentials of diseases, as pointed out earlier. In addition, when referring to illness, it is important to distinguish between chronic and acute. While *acute* indicates a rapid onset and short course, *chronic* designates a long-lasting path. Although most researchers would agree that one of the most salient characteristics of chronic diseases is that the disease process must persist at least several months, the meaning of "chronic" has been found to lie in the eye of the beholder (Rabin *et al.* 2004).

In agreement with the idea that those who experience chronic illness are the most appropriate to define the individual view of the experience of chronicity, and there may be an infinite variety of possible views, researchers need, however, to consider the broad-spectrum understanding of chronic illness to synthesise the different views of individuals with chronic diseases. A definition of chronic illness that highlights key issues of the concept is the following:

The conditions fulfil the accepted understanding we have of both chronic (of long duration or apt to recur) and illness (a state of suffering caused by a disease)(Little 2004, p. 201).

This definition is relevant in the context of this research as it coincides with the understanding emerged from the data about the characteristics of continuing suffering in the cancer experience (as we shall see later).

Chronic diseases, such as heart disease, cancer, and diabetes are diseases that are prolonged, do not resolve rapidly, and rarely cure is complete (Centre for Disease Control and Prevention 2003). Chronic illnesses show periods of remission of

symptoms interrupted by periods of acute exacerbation requiring physical management. Psychologically, chronic diseases have also great impact on both individuals and family members who may learn to manage the physical, social, emotional, and spiritual concerns in family's long term (Lubkin & Larsen 2002b). Given the burden of chronic diseases, prevention, treatment, and control of chronic diseases are central for healthcare services (Wolbeck Minke *et al.* 2006). The interest in chronic illness management is such that a UK initiative programme was developed to provide the appropriate resources to meet the needs of those with chronic illnesses and empower self-care management of their own long-term condition. This initiative was called as *The Expert Patient: A new approach to chronic disease management for the 21st century* (Department of Health 2001). While acute diseases usually involve rapid adjustment to stressful events, long-term sequelae of chronic illnesses necessitate adaptation in different life domain across the chronic illness trajectory (Stanton *et al.* 2006).

In relation to dealing with illness that persists for a long time, the group of cancer survivors can be considered as experts (Deimling *et al.* 2002, Stephens 2004). Many researchers and practitioners have shared recognition of the chronic nature of cancer. Likewise, many patients conceptualise their cancer as chronic or cyclic illness (Rabin *et al.* 2004). However, it is only in recent times that the understanding of the course of cancer has changed from an acute terminal illness to a chronic illness (Polinsky 1994). This shift has in parallel led to further investigations in cancer survivorship and quality of life in survivors of cancer. Similar to other chronic illnesses, cancer and its treatment cause physical, emotional, and social sequelae and require medico-psychosocial interventions over time (Mellon *et al.* 2006). For some, the “price of survival” is very high (Redler 1994), particularly in relation to the needs of long-term cancer survivors and the problem of emotional adaptation to cancer (Bard 1997).

The above evidence highlights the understanding of public health services, researchers, practitioners, and even patients about the view of cancer as a chronic illness characterised by long duration and enduring suffering. Despite the increasing culture of cancer survivorship and the diversity of studies investigating issues of

cancer at different points of the illness trajectory, Tritter and Calman (2002) has questioned whether cancer could be categorised as a chronic disease. According to the authors, four main characteristics distinguish cancer from most other chronic diseases. First, cancer is not an illness but rather a categorisation covering a range of different pathologies that are characterised by malignant cell replication. Second, chronic illness is incurable whereas some types of cancer can be cured. Third, cancer treatments differ from those of the majority of chronic illnesses in that they are complex and involve multiple medical disciplines, such as oncology, surgery, therapy, and palliative care. Fourth, the fact that the diagnosis of cancer is acute and needs urgent treatment contrasts with the diagnosis of chronic illnesses, which may emerge over time and seldom entail urgent treatment (Tritter & Calman 2002). This last study suggests that views of cancer as related to chronic illness may be divergent within literature. Although it may appear that this opposing view is detrimental, far from it, critiques of the understanding of cancer as a chronic illness allow researchers and health professionals to continue discussion and advance knowledge of the particular characteristics of cancer.

One of the most important developments in relation to care for individuals with chronic conditions is the shift in emphasis away from acute care management to care management over time. Notably, the trajectory framework by Corbin and Strauss (1992) is of the most significant models for the management of chronic illnesses.

THE CHRONIC ILLNESS TRAJECTORY FRAMEWORK

The Chronic Illness Trajectory Framework is a conceptual nursing model developed for the management of chronic illness (Corbin & Strauss 1992). The concept “trajectory” first emerged with Glaser’s and Strauss’s study of dying patients (Glaser & Strauss 1965), later to become the influential Chronic Illness Trajectory Framework (Corbin & Strauss 1992). The central concept of the framework is a trajectory, or illness course. The illness trajectory refers to a series of events within the course of an illness that are interconnected and inseparable. The trajectory is total

in that it does not isolate events but presents all events that appear as essentials to form to the course of illness (Corbin & Strauss 1992). Besides, the concept of trajectory refers not only to the physiological symptoms of a patient's disease, but also to the impact of the illness on the social world of those involved in managing the course of illness (e.g. patients, families, nurses). Overall, the term *trajectory* replaces the notion of process with a more complex and holistic view of the sequence of events in illness.

Within the trajectory, there are eight common phases that involve changes in health status and that change over time. The first stage, namely *pre-trajectory*, corresponds to the time before the onset of symptoms and the diagnosis. It emphasises the preventive phase, which is important in the management of chronic illness, as discussed earlier. The second phase known as *trajectory onset* represents the diagnostic time and it is the time when symptoms appear. During the *crisis* phase, the individual experiences a life-threatening situation because of the impact of disease. The next stage known as the *acute* phase is the time of active treatment and medical and nursing interventions. During this phase, individuals may require to be in hospital to receive treatment or to prevent complications associated with the illness or the side effects of medical treatment. The individual moves on to a *stable phase*, which is recognised as a period of symptom control that may require, however, certain types of intervention. Next is the *unstable phase* that consists of the period when the person may experience sequelae of treatment and illness, usually not requiring rigorous management at hospital. During this phase, the individual should adapt to the physical and psychosocial changes of the situation. After a short or longer period, the individual may experience a progressive deterioration resulting in great physical and psychological disability (this period is identified as the *downward phase*) to such a point that the person may enter the *dying phase* that is characterised by impending death.

An important feature of the phases of the trajectory is that the sequences of events are not linear. Each phase includes sub-phases which have movement in either direction along the illness course. Variation in the essentials of the phases also

occurs. “While the overall phase might be upwards (as in comeback), downward (as in deteriorating and dying), or even level (as in stable), nevertheless within any particular phase there might be periods of several weeks or even months that can be characterised as a reversal, plateau, upward movement or a drop” (Corbin and Strauss 1992, p. 16).

The trajectory framework which was first developed in 1992 and updated in 1998 (Corbin 1998) has been influential in practice, teaching, and research. Over the last 30 years, the framework has been applied to different patient groups, such as cardiac patients (Burton 2000), diabetes (Walker 1992), and cancer (Dorsett 1992, Robinson *et al.* 1997). The following section examines the phases of the trajectory of cancer in particular.

PHASES OF THE CANCER TRAJECTORY

Previously, we have seen that the phases of an illness trajectory do not correspond to a rigid framework. This dynamism may explain the different models proposed in the literature to describe the experience of cancer. Mullan (1985) conceptualised it as “seasons of survival” that comprised acute, extended, and permanent stages. The experience surrounding the initial diagnosis of cancer was defined as “acute survival”. The “extended survival” is when the person with cancer is dealing with the uncertainty of treatment and prognosis. Finally, the “permanent survival” is when the person is considered cured from cancer but still experiences its physical and emotional impact (Mullan 1985). Mullan’s conceptualisation of survivorship emphasised the experience of cancer as a continuum, ongoing process rather than a stage of survival. It is not just about medical outcomes but it is the experience of living with, through, or beyond cancer.

A more recent model is the Trajectory of Cancer Recovery based upon the Chronic Illness Trajectory Framework (Dorsett 1991, Dorsett 1992). The recovery model is characterised by a perspective of health recovery at any moment in time illness. The

process of recuperation consists of three subprocesses that occur concurrently: absorption, assimilation, and accommodation. Absorption refers to the initial immersion in a distressing event, such as the beginning of chemotherapy. Assimilation involves understanding and finding the meaning of the situation being experienced. An illustration of this phase given by Dorsett was the search for meaning of cancer diagnosis. Accommodation consists of integrating changes occurred in the patient's life. Whether in or off treatment, in remission or survival, in recurrence or terminal phase, recovery is a continuum process having physical, functional, cognitive, and affective dimensions that help the person move on toward the recuperation of health. What is important is "the recuperative powers of the individual when beset by illness" (Dorsett 1992, p. 33). Therefore, the emphasis of recovery is on the social and psychological aspects of surviving cancer. That is, the recovery model recognises the person as the shaper of the process, as opposed to the illness trajectory model that focuses on medical phases and professional interventions. In addition, the recovery model highlights a difference in perception from one that is based on illness ending in death (such as Corbin and Strauss's illness model) to one that is oriented toward survival.

Independently of how authors conceptualise the cancer trajectory, the literature suggests that each change in the illness course brings with it its own worries and challenges. Although the *experience* of cancer is a dynamic process of adaptation with no artificial (or medical) boundaries (Clarke-Steffen 1997), most studies have focused on issues for cancer patients and families at specific times in the illness experience, presumably to examine each stage in depth, and better understand the experience of cancer as a whole. In this study, the cancer trajectory is viewed as a continuum process of eight phases, including pre-diagnosis, diagnosis, treatment, remission and survival, recurrence, treatment for recurrent cancer; and finally dissemination and death (see Figure 1).

Finally, attention should be paid to the varying options that patients have after treatment for recurrent cancer. While some people will survive long term after treating their cancer recurrences, and will even achieve a cure, others will experience

disease progression. Generally, cancer can take three trajectories (see Figure 1). First, symptoms of the disease can disappear and cancer is said to be in remission again. When remission remains for years, the person can experience long-term survival. Second, cancer can take a relapsing course and alternate periods of remission with periods of exacerbation of the disease and new treatment. Third, the course of cancer can take a progressive trajectory, meaning the disease disseminates and there is no chance for stable illness. Signs and symptoms of cancer will worsen gradually leading to the dissemination of the disease, and ending with death (National Cancer Institute 2006). Estimated life expectancy at the terminal phase of cancer is usually considered in terms of blocks of time, including from months to a year, from weeks to months, and from days to weeks (National Comprehensive Cancer Network 2003). Treatment is said to be palliative, aiming at relieving symptoms and improving quality of life for the dying patients and their family members.

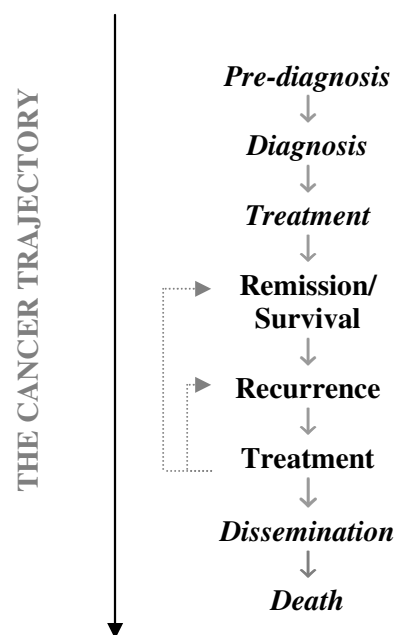


Figure 1. Phases of the cancer trajectory (based on data from Corbin & Strauss 1992, Corbin 1998, Frost *et al.* 2000, Morse & Fife 1998, Woog 1992).

It is within the scope of this research to focus on patients' and families' experiences of cancer recurrence, but literature regarding the different periods before the recurrent phase of cancer has been included in this review in order to contextualise the experience of recurrence. This section will briefly review the psychosocial responses of patients and families to the phases of pre-diagnosis, diagnosis, treatment, and remission and survival to introduce the following section, which will review the psychosocial issues during the recurrent phase of cancer.

PRE-DIAGNOSIS

This phase extends from discovery of symptoms or signs known to be a possible cancer indicator, such as a breast lump, severe pain, and blood in the stool, to diagnostic tests. Although survival rates are increasing, a cancer diagnosis is still socially regarded as a death sentence marked by pain, suffering, uncertainty, fear, and death (Clarke & Everest 2006, Fife & Wright 2000, Flanagan & Holmes 2000). The diagnostic tests themselves, such as mammographies, colonoscopies, biopsies, and scans, may be difficult to tolerate because of pain and phobias of medical procedures.

This initial phase of cancer certainly has an impact on how much individuals and families experience distress due to the fear of cancer. Families fear that symptoms correspond to cancer, and hope not to hear the fateful word. The idea of having cancer may contribute to patients delaying seeking help from the first onset of symptoms (Smith *et al.* 2005). The time surrounding diagnosis is indeed among one of great distress for patients because of the "waiting and not knowing" experience. From this moment, the trajectory of cancer begins, and uncertainties and fears with it (Murphy 1999). Although research about the pre-diagnosis stage is limited, a study (Leydon *et al.* 2003) supports the importance of viewing the cancer journey as including the time leading up to a diagnosis of cancer.

DIAGNOSIS

Diagnosis is when patients and families confirm their most dreaded thought and hear “you have cancer”. The diagnosis referred to as “I could die of this” in the book, *The human side of cancer: Living with hope, coping with uncertainty*, brings anticipated emotions of fear about chemotherapy side-effects, uncertainty about the future, and fear of the possibility of death (Holland & Lewis 2001). For many patients and relatives, the diagnosis of cancer results in anticipatory grief at the time of diagnosis. Dr. Jimmie Holland, psychiatrist and pioneer in psycho-oncology, has identified three emotional phases after diagnosis of cancer (Holland *et al.* 1997). Phase I is usually marked by disbelief, denial or despair, generally lasting about a week or so. In Phase II, reality is recognised and patients may become anxious and depressed. Phase III generally represents a longer-term adjustment, generally lasting weeks to months.

While cancer survival has improved considerably, the emotional impact of the diagnosis for patients and family members has essentially remained the same. The quality of adaptation to cancer diagnosis largely depends on personal, cognitive, family, and social resources (Baider *et al.* 2005). Besides, the clinical reality, including disease stage at time of diagnosis, cancer site, symptoms, and prognosis, is influential on how individuals and families adapt to cancer (Suinn & VandenBos 1999). The impact of cancer also appears to depend on how diagnosis is communicated. Schofield and colleagues (2003) found that communication strategies, such as giving the patient as much information about their diagnosis as desired, talking about the patient’s feelings, and being reassuring, produced positive patient outcomes. This approach is important, given the emotional distress cancer causes on individuals and families.

Growing research has thrown light to the fact that the diagnosis of cancer has profound impact on individuals and families (Baider *et al.* 2000, Northouse 1984). Cancer has been described as a crisis for family members (Blanchard *et al.* 1997). Besides the physical burden of the disease, the lives of both patients and family members are affected from the point of diagnosis (Fitch *et al.* 1999). Those close to a

person diagnosed with cancer experience a wide range of emotional reactions to the illness, and have information and emotional needs after the diagnosis (Kilpatrick *et al.* 1998, Rees & Bath 2000).

TREATMENT

Besides the sudden confrontation with a life-threatening and still stigmatised disease, both cancer patients and their families have to confront treatment. This phase consists of the time from going for treatment, dealing with its effects, attending check-ups and surveillance schedules involving x-rays, scans, blood taking, and having to manage the health care system itself. Patients may undergo only one mode of treatment, such as surgery, or may need a combination of treatment (e.g. surgery, chemotherapy, and radiotherapy). In addition to these modes of treatment, patients have to deal with overwhelming side effects such as nausea, pain, anorexia, fatigue, and alopecia (Ahles 2005, Mock & Olsen 2003). These symptoms have a direct impact on how much patients suffer not only physically but also emotionally and spiritually (Arantzamendi & Kearney 2004).

The treatment phase provokes emotional turmoil in families because it is at this time when family members, especially spouses, become aware of the impact of the cancer experience on themselves and their ill relative (Samms 1999). Changes of roles and dynamics in the family can cause great anxiety and distress in its members (Lewis *et al.* 1993). Frequent hospitalisation for the treatment causes additional family disorganisation, resulting in more suffering in the family (Giovannetti-de-Jesus & Bergamasco 1998). Helplessness, fear, and anger are reported as the most stressful emotions experienced among those who have family undergoing chemotherapy, especially when the patient is the mother and the wife in the family (Fitch *et al.* 1999, Wilson & Morse 1993). In an attempt to help the patient, relatives seek to ensure that his/her relative does not feel alone or abandoned. It is a question of “being there” to support, to communicate, and often to keep things normal, or as normal as possible (Thomas *et al.* 2002). Managing the feelings of the patient with

cancer during the treatment regimen appears to be one of the major difficult tasks for family members. This is because at the same time as managing the emotions of the patient, family members must deal with their own feelings. In addition, the economic burden as a result of medical and day-to-day living expenses and travelling costs adds to the burden of cancer, which may be harder to manage when changes occur in the workplace (Hilton *et al.* 2000).

Within the treatment experience, there is the underlying issue of what therapeutic effect the treatment is having. Will treatment be effective and remission and later survival be possible?

REMISSION/SURVIVAL

The concept of remission is well established in the medical/oncology literature. The concept is defined as the disappearance of signs and symptoms of cancer in response to treatment (National Cancer Institute 2006). Remission has been categorised under partial or complete remission. Partial remission is the decrease in the size of a tumour or in the extent of cancer in the body. Complete remission, a condition also known as complete response or remission, is the absence of all signs and symptoms, although this does not always signify the cancer has been cured (National Cancer Institute 2006). To determine the status of remission, a series of tests and examinations are conducted such as blood tests, chest X-rays, scans, simple medical examinations, and more complex molecular tests that detect disease beyond the capability of morphological examination (Mandrell & Pritchard 2006). If tests show that the patient is responding to treatment because the cancer has shrunk, this is referred to as partial remission. When tests are found to be under normal scores and there is no evidence of disease, we talk about complete remission (Redaelli *et al.* 2005). With regard to the length of time in remission, temporary remission has been identified as the period of time (usually short) after the end of treatment during which a patient remains in remission (MedicineNet.com 2006). In contrast, permanent remission

implies that the patient is disease-free for a few years, and his/her cancer might be cured.

In relation to the concept of survival, definitions are divergent. For epidemiologists, the starting point for cancer survival is commonly expressed as 5-year free interval after diagnosis (Berrino *et al.* 1999). There is also the view of survival as the time occurring from initial diagnosis of cancer to death, as discussed earlier in Mullan's seasons of survival. A common view of survival is embodied by the concepts of short-term and long-term survival. Short-term survival is the period from diagnosis up to 5 years, as opposed to long-term survival that involves the length of time a person is alive taken from diagnosis to over 5 years. The period of 5 years after diagnosis is taken because most recurrences occur within 5 years of diagnosis (Gotay & Muraoka 1998).

In analysing the aforementioned terms, correspondence may be made between temporary remission and short-term survival versus permanent remission and long-term survival. However, the concepts are often used to communicate differences. I have come to the conclusion that remission has been usually used to refer to the physiological state of cancer (e.g. "your cancer is in remission"). The concept of survival, connected to survivorship, appears to involve a more complex, multifaceted aspect of the state of remission. It captures in addition to disease-symptom dimension other domains such as the emotional, social and spiritual. Indeed, researchers have paid growing attention to the psychosocial issues in cancer survival over the last fifteen years (De Boer *et al.* 1999, Redler 1994).

There is no agreement about the definition of a long-term cancer survivor (Hewitt *et al.* 2006). Views differ according to who defines the concept. For researchers, a long-term survivor may be a patient who has survived for five years or more after end of treatment (Leigh 2001). However, the long-term survivor "might be balancing recovery from the original disease with the challenges of chronic or late effects of treatment" (Leigh 2001, p. 235). Referring to breast cancer, a long-term survivor has been defined as a person who has lived for five years from breast cancer diagnosis without recurrence and, although she is disease-free, she may experience physical,

psychosocial, spiritual, and sexual sequelae due to breast cancer (Vivar & McQueen 2005, p. 1-2).

In the absence of distinctive evidence about the concepts of remission and survival in relation to the length of the disease-free interval, in this study I will refer to a patient in remission as the person who has finished treatment and has had no signs of the disease for a 6-month period after the end of treatment. This time frame has been chosen because individuals may be still dealing with the acute problems arisen from their disease and treatment. A short-term survivor will be defined as the person who has lived from cancer diagnosis up to five years without evidence of the disease. Finally, a long-term survivor will be defined as the person who has lived for over five years from diagnosis without evidence of the disease.

The shift to the view of cancer patients as cancer survivors has in parallel changed the research focus from treatment of disease alone to the measurement of this broader concept, defined as quality of life (QoL). QoL refers to a multidimensional, subjective concept including aspects of physical, psychological, sexual, spiritual, and social wellbeing, and not merely to the absence of disease (Zebrack 2000). QoL in cancer survivorship has been broadened to include not only the extension of life, but also the client's perception relating to quality of survival (Dow *et al.* 1999). A growing body of literature indicates that cancer survivors may experience quality of life disruptions, which include physical, psychological, social, and spiritual impairments (Bottomley *et al.* 2005, Ganz *et al.* 1996, Wenzel *et al.* 2005, Wyatt & Friedman 1996). Quality of life of long-term breast cancer survivors has been reported to differ from healthy women (Helgeson & Tomich 2005, Schroevers *et al.* 2006). A review of the literature has also indicated differences in psychological wellbeing between survivors and healthy women, particularly in relation to physical, psychological, social, and spiritual changes after the end of treatment (Vivar 2005c, Vivar 2005d).

Apart from the physical sequelae that cancer survivors may experience in their survivorship (Curt *et al.* 2000, Thors *et al.* 2001), they may experience psychological concerns such as uncertainty over the future (Mast 1998) and fear of recurrence (Lee-

Jones *et al.* 1997, Vickberg 2001, Wenzel *et al.* 2002). In fact, one of the most frequently mentioned components of distress among cancer survivors is fear of cancer recurrence, even though there is no evidence of disease.

Many people diagnosed with cancer survive long-term after the end of treatment. However, oncologists are usually hesitant to say that someone is cured of cancer because cancer may recur, the next phase in the cancer trajectory.

Recurrent phase of cancer: the psychosocial issues

Recurrent cancer in a patient poses daunting challenges for families. The profound sense of suffering in a patient makes it especially painful for loved ones because the impact of recurrent illness reverberates throughout the entire family. Therefore, traditional views of cancer as an individual disease are discarded in this study in view of the recognition that the chronic nature of cancer affects both the patients and their families (Patterson & Garwick 1994, Whyte 1997). The aim of this section is to explore the psychosocial issues of cancer recurrence for patients and families. This study will later show that a family's current response to recurrence cannot be understood adequately apart from the experience of survivorship. That is why in this text family survivorship is viewed as part of the recurrent phase of cancer, and literature regarding this phase of the illness has been included in this section.

FAMILY SURVIVORSHIP

Many studies report that survivors experience persistent fear of recurrence and a greater sense of uncertainty about the future (Mast 1998, Wonghongkul *et al.* 2000). This set of emotions is traditionally known as the "Damocles syndrome". Fear of recurrence, referring to a perception of serious threat and a belief that cancer may return at any time, is one of the greatest psychosocial stressors confronting survivors and families (Lee-Jones *et al.* 1997, MacBride & Whyte 1998, Polinsky 1994,

Stephens 2004). Minor physical symptoms are feared to be signs of recurrent disease (Cameron *et al.* 1998). Symptoms related to the disease itself or treatment side effects are often distressing and may persist over time, as is the case of chronic fatigue after treatment has ended (Curt *et al.* 2000). However, when these residual symptoms become severe, anxiety increases and the fear exacerbates. In addition, fear of recurrence is often triggered by medical follow-up, resulting in many survivors feeling great anxiety before routine appointments.

Along with the fear of recurrence, people experience a greater sense of vulnerability after the end of treatment. When distress is high and endures over time, survivors may experience posttraumatic stress disorder (Black & White 2005, Deimling *et al.* 2002). However, distress is not experienced with the same intensity throughout the survival trajectory. Long-term survivors (5 or more years post-diagnosis) have reported less worry than more recent survivors (Tuinman *et al.* 2004, Wonghongkul *et al.* 2006). This may be because the risk of recurrence is maximal in the first five years (Gotay & Muraoka 1998).

Although the fear surrounding cancer is gradually diminishing, the disease continues to harbour aspects of stigma and discrimination. Discrimination may occur within the workplace solely because of a history of cancer (Hoffman 1991). Although return to work is a way of coping with cancer because it provides continuity and normalcy to life (Spelten *et al.* 2002), cancer survivors may experience discriminatory treatments including denial of new jobs, mandatory medical examinations, undesirable transfers, and hostility (Hoffman 1991). Consequently, many survivors experience a negative work re-entry (Carter 1994), and for some, employment discrimination can even result in a decision to stop work and retire early (Stewart *et al.* 2001). These studies clearly show that survivors of cancer experience some problems related to employment and work re-entry. The stigma of cancer as a disabling and fatal disease still lingers today, and can imply that return to work for survivors become challenging.

Added to this, is the challenge of healthcare services during survivorship. A publication of the National Cancer Institute reporting issues about life after cancer

treatment touched some sensitive aspects of health care services (National Cancer Institute 2002). It highlighted deficiencies in care for survivors of cancer, particularly in relation to communication between doctors and patients. It also stressed survivors might feel unable to express their concerns as they might feel it inappropriate to burden physicians with issues that might appear insignificant in comparison to those that were life threatening. Survivors may not count on professionals to receive a comprehensive approach to information and emotional support, and therefore, need to find complementary sources such as self-help groups (Vivar & McQueen 2005).

Although survivors adjust satisfactorily as time passes, physical and psychological sequelae may remain long after treatment completion, as reported in a study of breast cancer survivors interviewed 20 years after adjuvant chemotherapy (Kornblith *et al.* 2003). Others, however, have found opposing results. Yabroff *et al.* (2004) compared the burden of illness between a sample of 1823 cancer survivors and 5,469 individuals without cancer in a national, population-based sample. Contrary to their expectations, they found that long-term cancer survivors, even 11 or more years after diagnosis, showed statistically a significantly higher burden than their matched control individuals (Yabroff *et al.* 2004). Therefore, cancer survivors may experience poor physical and psychological health, which may become severe and end in psychological and psychiatric problems (Kua 2005, Saleeba *et al.* 1996).

Aside from the literature showing that survivors and families may experience psychosocial consequences of cancer, survivors have also reported good physical, psychological, and social functioning during survivorship (Ferrell *et al.* 2003, Tomich & Helgeson 2002). Many cancer survivors report positive survivorship sequelae such as greater purpose in life, improved relationships with others, and positive spiritual changes related to cancer (Dow *et al.* 1999, Vachon 2001).

Family members also experience the cancer illness with survivors. The long-term impact of cancer problems affects the whole family unit (Mellon & Northouse 2001). The diagnosis of cancer creates emotional turmoil within the family, disrupts roles and lifestyle, changes the communication between their members, and has an impact on the existential concerns related to suffering and death (Matthews 2003, Mellon

2002). It is not surprising, then, that some studies have indicated that spouses of patients with cancer reported increased distress (Northouse *et al.* 2000), and greater worry about recurrence than the patient (Northouse *et al.* 1995b). In an exploratory, cross-sectional study, Mellon *et al.* (2006) examined the quality of life of a random sample of 123 cancer survivors from 1-6 years post-diagnosis and 123 of their family caregivers (including spouses, siblings, children, and significant others). The authors found that the quality of life of cancer survivors was significantly higher than their family members who experienced higher fear of cancer recurrence. A relevant finding of this study was the role of social support during survivorship. While survivors perceived higher social support which was associated with higher quality of life, family members reported less support which was associated with lower quality of life (Mellon *et al.* 2006).

Besides presenting one of the few studies that have explored the quality of life of both cancer survivors and their family members, this study confirms the theory that care should not be addressed simply to survivors but should ensure the general wellbeing of families beyond their survivorship. A major challenge in health care services is to recognise family quality of life and deal with the psychosocial sequelae patients and families may experience following a diagnosis of cancer.

WHEN CANCER RECURS: FACING NEW CHALLENGES

Recurrence is when cancer comes back after a period of time during which the cancer is in remission (National Cancer Institute 2006). As described earlier, cancer may return to the same place as the primary tumour (local recurrence) or to another site in the body (in the region or distantly).

Despite the prevalence of recurrent cancer, psychosocial research on the experience of cancer recurrence has been limited. In the eighties, only two papers documented the experience of recurrence (Chekryn 1984, Weisman & Worden 1986), and one examined the fear of recurrence in breast cancer patients in remissions (Northouse

1981). In the nineties, authors paid greater attention to the psychosocial impact of cancer recurrence on the patients and their spouses (Given & Given 1992, Halliburton *et al.* 1992, Lewis & Deal 1995, Morse & Fife 1998, Northouse *et al.* 1995c, Northouse *et al.* 1995b). Over the last ten years, researchers' interest on the psychosocial impact of cancer recurrence seems greater, yet evidence is still insufficient compared with the abundant literature on issues for families in the terminal phase of the illness. This is curious given recurrence has been identified as "a traumatic event" (Cella *et al.* 1990).

The following subsections will provide an understanding of the reasons that make cancer recurrence distressing for patients and their families.

DEALING WITH THE DIAGNOSIS OF RECURRENT CANCER

As in the pre-diagnosis phase of the cancer trajectory, survivors undergo a series of tests before confirmation of recurrent cancer. Different procedures are conducted to detect suspected recurrent disease, including physical examination by oncologists, x-rays, computed tomography, magnetic resonance, and biopsy (National Cancer Institute 1997). However, this time is different from the first diagnosis because survivors and their families have feared that cancer could return, and they realise that the fear of recurrence is now a fact: "cancer is back again".

A descriptive study by Mahon and Casperson (1997) explored the psychosocial meaning of recurrent cancer in a sample of 20 patients diagnosed with recurrent disease within the previous 30 days. The authors found that the recurrence led patients to experience psychosocial concerns that were different from the initial diagnosis. Knowing that cancer had returned was devastating for patients because they were not prepared for this shock although they knew the chances of recurrence. However, patients with previous recurrences were not surprised by the diagnosis and were optimistic of a remission. The study concluded that all the patients reported fear of the future, particularly in relation to death.

LIVING WITH UNCERTAINTY

Recurrence in the family can have a profound negative impact, particularly in terms of living with uncertainty. The identification of recurrent disease causes the future to be viewed in terms of uncertainty and perceived loss. The patients and their families must again confront the issue that cancer may not be cured and the patient's life may be shortened (Northouse *et al.* 1995c). The initial hope for a cure disappears or diminishes and distrust in treatment arises (Herth 2000). As a consequence, individuals diagnosed with recurrent disease and their families are faced with uncertainty.

In terms of existential concern, uncertainty about the future can originate questions about mortality. When asked if recurrence posed any individual or family hardship, 83% of Chekryn's (1984) sample (12 women with cancer recurrence and 10 spouses) reported concerns about death. In a study comparing women's perspectives regarding the impact of ovarian cancer in remission and the impact of recurrent disease (Fitch 2003), the author found that 84% of women with ovarian recurrence reported fear of dying. Other research has suggested that the threat of death is "more real" after recurrence (Mahon *et al.* 1990), and that the meaning of recurrence is influenced by prior cancer-related experiences and dominated by death and death-related concerns (Mahon & Casperson 1997).

In a descriptive study of married couples' experiences with breast cancer recurrence (Lewis & Deal 1995), the core category of the study "balancing our lives" described how the couples lived with recurrence in managing everyday life, surviving, healing, and preparing for death. The sample consisted of 15 married couples who were interviewed an average of 10 months since recurrence. While the couples were learning to live with recurrence through accepting it, they prepared for potential death by talking about dying and afterwards. These findings show that recurrence means wavering between optimism about possible remission and the possibility of terminal illness and death.

FACING TREATMENT AGAIN

In contrast to treatment for a primary tumour, treatment for recurrent cancer is complex and still poorly defined (Ferrandina *et al.* 2006, Moran & Haffty 2002). Apart from the clinical challenges in treating recurrent disease, the challenges associated with treatment are important. Facing treatment and its side effects again is particularly challenging for patients, especially because treatments are severe and sequelae of primary cancer and its treatment may exist (Howell *et al.* 2003). In a study of 40 patients diagnosed with recurrent cancer, 78% of the sample reported that news of their recurrence was more upsetting than news of their initial diagnosis, mostly because decisions about treatment options were more difficult with the recurrence, side effects of treatment were more severe, and fear of pain was greater (Mahon *et al.* 1990). This may be also explained by the fact that patients with a recurrence have previous experiences of treatment, and they bring their memories with them (Mahon 1991). When the memories are disturbing, patients may be flooded with anticipatory anxiety.

Severe adverse effects of treatment including fatigue, alopecia, nausea and vomiting, bowel complications, cardio-toxicity, and pain add to the burden of recurrence (Edwards 2003). After a diagnosis of recurrence, the patient's body is no longer as strong as it once was. Physical sequelae of previous cancer and treatment, together with the recurrence of disease and side effects of current treatment may worsen the patients' health condition, and increase their distress during treatment (Munkres *et al.* 1992). This is supported by a descriptive, longitudinal study that described the difficulties of 34 patients initiating chemotherapy for cancer recurrence and their 38 family members (Halliburton *et al.* 1992). The main concern of families was related to the patient's health changes due to the recurrence and the effects of treatment, although families also mentioned concerns about family issues, finance, and the patient's psychological wellbeing.

Facing treatment for recurrent cancer is especially challenging for patients and families because treatment options are limited, thus patients have to undergo a combination of cytotoxic drugs which usually cause them severe side effects (Rose

2003). Chemotherapy, radiotherapy, surgery, hormonal therapies, bone transplantation, or a combination of treatments can be offered. The selection will depend on various factors, such as the type of primary cancer and the tissues that have been invaded by the recurrent cancer, the treatment patients have had in the past, and the age and general health (National Cancer Institute 1997).

In addition to side effects of treatment, complications can occur. For instance, specific complications of breast cancer recurrence are hypercalcaemia that aggravates symptoms of nausea, vomiting, or constipation; bone marrow metastases; spinal cord compression; and other severe problems that may threaten women's lives (Burnet & Robinson 2000). Therefore, adverse effects of treatment and complications of the disease have a great impact on the physical wellbeing of individuals with recurrent cancer. Frost *et al.* (2000) compared the physical, psychological, and social wellbeing of women with breast cancer at four stages of the cancer trajectory, including new diagnosis, treatment, remission, and recurrence. The authors indicated that the group of women with recurrent cancer experienced more difficulties compared to the other three groups in terms of health perceptions, impact on life, and medical interaction. Women with recurrent disease perceived themselves as less healthy than women newly diagnosed, in treatment, or in remission. Moreover, women facing recurrence reported a greater impact on their lives than the women in the other groups. An interesting finding was that the women in the recurrent group found communication with the medical team to be more difficult than the women newly diagnosed, in treatment, or in remission.

Research has found similar findings in relation to healthcare during the recurrent phase of cancer. Literature suggests that communication between patients with recurrent cancer and health professionals is different compared with a first diagnosis. Patients experiencing recurrence feel information about their treatment is inadequate compared to the extensive information they received during their first diagnosis (Howell *et al.* 2003, Mahon *et al.* 1990). Family members also perceive communication with healthcare professionals as superficial and poor during recurrent disease (Cella *et al.* 1990, Morse & Fife 1998). These findings suggest a need to

further explore issues surrounding the type of health care support during this phase of the illness. It is within the scope of this research project to describe patients' and family members' experiences of nursing care during recurrence, as well as nurses' experiences of caring for these families.

MANAGING PSYCHOLOGICAL PROBLEMS

Literature suggests that recurrence is a time of increased psychological distress for patients (Jenkins *et al.* 1991, Kennelly 2001, Mahon *et al.* 1990) and for partners of patients with recurrent disease (Morse & Fife 1998, Northouse *et al.* 2002a). As described above, recurrence brings back many negative emotions, which are different and may be more intense than those after first diagnosis of cancer. The husbands of women with breast cancer have been found to experience great distress and fear during recurrence, these emotions being sometimes more distressing than those of the patients themselves (Given & Given 1992, Northouse *et al.* 1995c). This may be due to an "excess of emotions", as family members have to deal with the impact of cancer on themselves together with fears and new responsibilities. As a consequence, spouses of cancer patients may experience poor quality of life during the cancer experience, as has been confirmed in a study of spouses of women with breast cancer (Wagner *et al.* 2006).

Longitudinal research suggests that there is a decrease in quality of life in women diagnosed with recurrent breast cancer (Bull *et al.* 1999). In comparing the psychological adjustment of women following the diagnosis of recurrent breast cancer and women with disease-free survival, Oh *et al.* (2004) found no differences between the two groups. The authors concluded women experiencing recurrence had relatively high quality of life, good interpersonal relationship, and good overall mood following recurrence. However, the authors did find differences between women with local recurrent disease and women with metastatic recurrence, these latter reporting poorer physical functioning and higher distress. Although the study by Oh (2004) had several limitations, including lack of information about the nature of the

women's treatment for their recurrence and lack of data indicating how ill the women with recurrence were, its findings suggest that patients diagnosed with recurrence should not consistently experience important psychological distress or quality of life disruption. The findings by Oh et al (2004) are supported by a controlled, prospective longitudinal study that compared a sample of 30 patients with breast cancer recurrence with a sample of 90 patients in remission (Andersen *et al.* 2005). Results from these studies suggest that emotional distress and social functioning of patients with recurrent disease may be similar to cancer survivors.

However, Okamura et al (2000) found that 42% of the patients with breast cancer recurrence suffered from psychological distress. A disease-free interval was found to predict a major adjustment disorder. That is, recurrence that occurred less than 24 months after first diagnosis seemed to have a greater psychological impact on patients than later recurrence. A younger age was also shown to relate to higher psychological distress in patients with breast cancer recurrence. In a later study exploring the prevalence of psychiatric disorders following first breast cancer recurrence, Okamura and colleagues (2005) indicated that major depression was common in patients with recurrent disease. In particular, 22% of the 50 women with recurrent breast cancer who participated in the study manifested a type of psychiatric disorder (Okamura *et al.* 2005). The divergent views in the literature suggest further randomised controlled trials on psychological responses to cancer recurrence.

IS RECURRENCE MORE STRESSFUL THAN INITIAL DIAGNOSIS?

There is a mixed picture about whether the psychosocial impact of cancer recurrence is more distressing than the first diagnosis of cancer. Weisman and Worden (1986) hypothesised that recurrence was more disabling and discouraging than the impact of the initial diagnosis but their research findings did not confirm this. Levels of distress in patients with recurrence were not significantly different from those of patients newly diagnosed with cancer. Other studies have not found differences in emotional distress and social functioning between patients with recurrent breast cancer and

those disease-free (Andersen *et al.* 2005). However, cross-sectional research and retrospective reports suggest that cancer recurrence can be equally or more stressful than the original diagnosis of cancer (Burnet & Robinson 2000, Northouse *et al.* 1995b). According to Cella *et al.* (1990), the central issue in cancer recurrence as a traumatic event seemed to be the loss of hope. Some authors, however, found no significant differences between newly diagnosed cancer patients and those with recurrent cancer regarding levels of hope (Ballard *et al.* 1997).

According to Burnet and Robinson (2000), “the issue of whether one experience is more or less distressing than another is debatable. Rather, what seems relevant and important are questions related to what is distressing and upsetting about the experience and what health care professionals can do to help” (p. 32). If that is really the importance, health carers need to help patients and their family members cope with cancer and treatment by understanding the suffering of families as a response to recurrence.

THE SUFFERING OF PATIENTS AND FAMILIES LIVING WITH RECURRENCE

The above studies show that the diagnosis of recurrent cancer intensely challenges patients’ and families’ lives, imposes individual and family threats, and causes alterations in many domains of life, including the physical, the psychological, the existential, and the social. Literature shows that patients and their families respond to recurrence with feelings of sadness, fear, anguish, and despair. The experience of recurrence may imply the loss of hopes and goals and the uncertainty of life. This diversity of negative emotions can be brought together under the concept of suffering.

Despite the clear importance of suffering, it is only in the last two decades that the concept has received greater attention in the medical and nursing literature. Few texts are available that explore the meaning of suffering associated with illness (Arman *et al.* 2004, Duggleby 2000, Kane & Primomo 2001, Kowalik 1998, Rydahl-Hansen

2005). In nursing research, Janice Morse has probably contributed most to the understanding of the concept over the last decade (Morse 1997, Morse 2000, Morse 2001, Morse *et al.* 2003, Morse & Carter 1995a, Morse & Carter 1996b, Morse & Penrod 1999). It would be interesting to discuss her evolving theory of suffering but the aim of this section is not to do so. Rather, this section will present a definition of suffering within the context of this research.

An early definition of the concept described suffering as “a state of severe distress associated with events that threaten the intactness of the person...suffering is experienced by persons and not bodies” (Cassell 1982, p. 640). This traditional definition of suffering, widely cited by authors and relevant because it comprises more than physical pain, is however limiting in terms of its inclusiveness. The definition seems to refer particularly to the individual aspect of suffering. This is not surprising bearing in mind that, to date, the phenomenon of suffering has been usually viewed within the context of pain and suffering of patients (Flaming 1995). However, suffering is viewed in the current study as being experienced by persons and not merely by bodies. This is because suffering from cancer has been found to take on a family dimension in that cancer is not an individual experience but it is a family experience (Lindholm *et al.* 2002). Therefore, the concept is not limited to physical pain but comprises its psychological and social experiences. Likewise, suffering is understood as a shared sentiment that is experienced by and with other social individuals. This view of suffering has been identified as “social suffering” (Wilkinson 2005).

Suffering does not guarantee life will be happy after a period of suffering (Moulyn 1982). However, Frankl (1984) believes that suffering helps individuals find purpose in life, meaning that the effects of stressful experiences are not uniformly negative and may be associated with profound positive outcomes. There is evidence supporting the gain from suffering in various domains, including illness (Barron 2005, Katz *et al.* 2001, Mohr *et al.* 1999), torture (Frankl 1984), and disasters (Bournes & Ferguson-Paré 2005, Joseph *et al.* 1993). Particularly, the experience of cancer has been associated with posttraumatic growth in cancer survivors and their

partners (Manne *et al.* 2004, Thornton 2002, Thornton & Perez 2006). Family gain has been also found in suffering, including close relationships in couples (Dorval *et al.* 2005). Beyond managing suffering caused by a life-threatening illness, studies document the potential for personal and relational growths. As families become more resourceful, they are better able to understand the meaning of suffering. Suffering may become an opportunity for families to reappraise life priorities and decide what is important and secondary in life (Chesla 2005).

Alleviation of suffering is regarded as one of the main objectives of nursing, along with physical and psychosocial care for individuals (Travelbee 1971). Nurses can help patients deal with the suffering of cancer by providing effective supportive care (Molassiotis & Foubert 2005). In particular, a main challenge for cancer nursing is to deal with cancer-related suffering.

Towards alleviation of family suffering in cancer services

Nursing has a central role in the care and treatment of cancer. Not only do nurses accomplish practical tasks, but also play a relevant role in providing psychological and emotional support to both patients and family members through the different phases of the cancer trajectory (Ferrell *et al.* 2003). The purpose of this section is to present not only the ways nursing seek to recognise the suffering of cancer patients and families, but also to show that family nursing is important to a family-based approach in cancer services.

RECOGNITION OF SUFFERING COMES FIRST

Nurses are in a unique position to observe and understand how patients and families are experiencing the stressful experience of cancer. While nurses may not be able to

relieve emotional suffering in the same degree as they can physical discomfort, the simple recognition of suffering in the patients and family members appears as the first step in good quality of cancer nursing. However, understand the suffering of patients and families is insufficient. Of importance is that health professionals seek to alleviate suffering once it has been recognised.

RECOGNITION OF SIGNS OF SUFFERING

The impact of cancer depends on multiple factors (Lubkin & Larsen 2002a). Likewise, suffering is likely to be multifactorial in origin. Therefore, several aspects must be considered when collecting information on suffering, including the meaning of cancer for the person and family, type of cancer, prognosis, level of disability, hope, age, sex, cognitive capacity, family support, social support systems, and cultural beliefs and values. Culture has been shown to be a strong determinant in beliefs, meanings, and attitudes towards cancer (Richer & Ezer 2000). Therefore, it is important to consider cultural aspects when seeking to understand the meanings of cancer (Donnelly 1995). From this standpoint, culture provides a person with beliefs and values for understanding and responding to suffering. Although it is desirable for nurses to be familiar with the life characteristics of the major cultural groups under their care because this will permit recognition of the needs of culturally different individuals (Canadian Nurses Association 2004, Grahn *et al.* 1999, Scheider & Barsoax 1997), the best way to understand suffering is to listen carefully to the person's opinions and beliefs. Open and compassionate communication is essential to understand the suffering of families living with cancer. Developing a healing atmosphere, based on listening, respect, kindness, a mutual relationship, and spending time at the bedside appear to be essential elements to help individual open up to their concerns and suffering (Jones 1999, Richardson 2004, Watson 2003). Ryan *et al* (2005) mentioned techniques such as active listening, using open questions and emotional words, and responding to patients' emotional cues as important in detecting suffering.

However, patients who are distressed have difficulty expressing their feelings, whereby suffering takes other expressions (Younger 1995). To help recognise signs of suffering, Younger (1995) offered a useful conceptualisation of the “language” of suffering. Suffering can be divided into three phases: mute suffering, expressive suffering, and finding an autonomous and authentic voice. Mute suffering is characterised by the person being unable to convey her experience of suffering, thus using other expressions such as complains, crying, or physical pain. Expressive suffering is characterised by a sense of sorrow. Gradually expressive suffering gives voice to experiences and feelings and the person finds an autonomous and authentic voice. Nurses should help cancer patients and their families discover an authentic voice through helping them move from mute suffering to expressive suffering.

Another way of identifying suffering is by linking verbal and facial cues (Morse *et al.* 2003). Verbal and nonverbal communication can reveal important information about a person’s feelings. Therefore, nurse should pay attention to body posture and movement, facial expressions, and auditory cues including amount of speech, tone of voice, and word choice. This data will certainly be useful in identifying signs of suffering although this approach may be insufficient. Recognising suffering is very difficult because each person is unique and does not experience suffering in the same way. Besides, a literature review has shown that patients tend to conceal their feelings from oncologists because they believe it is not the role of doctors to deal with their emotional worries (Ryan *et al.* 2005). As discussed above, suffering may be hidden, resulting in the difficulty of diagnosing suffering (Cassell 1999). In addition to the collection of qualitative data of suffering, recognition can take one step further.

USING SCREENING TOOLS TO RECOGNISE SUFFERING IN CANCER PATIENTS AND FAMILY MEMBERS

Screening tools can be useful to assess psychosocial dimensions of individuals in a health context and to identify needs of a population that requires specific treatment

and care (Polit & Beck 2004). Besides, the use of sensitive assessment tools in practice is found beneficial to guide diagnosis, determine therapeutic approach, and help professionals communicate with precision (López-Alonso & Morales-Asencio 2005). Despite the benefits of the use of psychosocial measures, their use is generally unusual in cancer practice. Time pressures and clinical constraints have been reported to be the major barriers to the use of these measures (Morris *et al.* 1998).

Although these measures are rarely used in practice, they are more widely used in research. In cancer research particularly, standardised psychosocial assessments are increasingly being developed in order to appraise psychosocial aspects of cancer. Quality of life tools have been developed to use with specific populations, including cancer survivors (Ferrell 2003), patients with advanced and terminal disease (Cohen *et al.* 1995, Steinhauser *et al.* 2002), and caregivers of patients with cancer (Edwards & Ung 2002). Moreover, there are a number of tools to assess depression in cancer patients, such as the Hospital Anxiety and Depression Scale (Love *et al.* 2004, Mykletun *et al.* 2001), validated for a Spanish population also (Herrero *et al.* 2003, Quintana *et al.* 2003). Given the limited information about families' psychological outcome in cancer, the Family Relationships Inventory (FRI) has been used to assess family dysfunction and psychological distress experienced in families of cancer patients, including levels of depression and anxiety (Edwards & Clarke 2005). In palliative care, a great number of tools have been developed to assess the burden of cancer in caregivers, as illustrated by a review publication (Kinsella *et al.* 1998).

For a tool to be effective, it must be sensitive to a specific population. A precise instrument that discerns the needs of patients with recurrent cancer and their family members seems important for nurses involved in caring for families living with cancer recurrence. However, no measure to assess recurrent cancer-related needs has been developed to date (to my knowledge). Clinicians and researchers with interest in assessing psychosocial aspects of patients with recurrent cancer and their family members have used generic instruments. For instance, Oh *et al.* (2004) used a combination of standardised measures to examine the psychosocial adjustment of women with recurrent breast cancer 1-5 years after initial diagnosis and following

the diagnosis of recurrence. The authors used, among seven other measures, the Medical Outcomes Study SF-36 that assess eight areas of health (physical functioning, physical role limitation, physical pain, social functioning, emotional wellbeing, emotional role limits, energy/fatigue, and general health perceptions) and the Revised Dyadic Adjustment Scale (RDAS) that evaluates marital relationships. In assessing patients' and family members' quality of life within 1 month after recurrence, Northouse *et al* (2000a) used the generic health-related measure of the Medical Outcomes Study SF-36 and the Functional Assessment of Cancer Therapy (FACT) assessing the physical, social/family, relationship with doctors, emotional, and functional well-being. A new instrument, named the Pictorial Representation of Illness and Self Measure (PRISM), has been developed and preliminary validated to assess the perception of suffering caused by illness (Büchi *et al.* 2002, Rumpf *et al.* 2004). Although the innovative measure has been used in a non-cancer population, what seems important is that these studies have presented preliminary data supporting the reliability and validity of the tool to assess suffering associated with illness.

Collecting information from both the use of psychosocial instruments and a compassionate, interpersonal relationship is important for recognising suffering of patients and families facing cancer. This information will be valuable for planning individualised, holistic interventions for alleviating suffering in the families. However, for good caring to be provided, nurses need first to confront their own feelings about cancer and address how these influence their interaction with patients and families. Following, research about nurses' experiences with cancer is discussed.

NURSES' EXPERIENCES WITH CANCER

Research exists describing how nurses can provide guidance, information, support, and other practical information to the family of a patient with cancer (Molassiotis & Foubert 2005, Rees & Bath 2000, Wilkes *et al.* 1999). According to nurses, one of the most common responses to anxiety experienced by patients is to encourage them

and cheer them up, along with identifying symptoms and offering explanation of the symptoms (Motyka *et al.* 1997). In the awareness context of dying, the provision of emotional care is based on touching, listening, expressing empathy, attending to the patients' wishes, comforting, encouraging, and being with the patient and the family (Kuuppelomaki 2003, Lewis 1990). However, nurses report barriers that impede their ability to good care, especially in the emotional dimension. While nurses consider the provision of emotional support important, lack of time and skills limit this type of care (Wilkes *et al.* 1999). Besides, education about emotional management is limited, meaning that nurses have to gain skills informally in the workplace through life experience (Staden 1998). The dominance of physical care is evident in nursing practice, as is the case in oncology medicine. The provision of emotional care for cancer patients is usually provided after physical interventions are completed and if time is available.

Research has shown that nurses have difficulty in the provision of emotional care for the patients and families with cancer. However, the detailed experiences of nurses and their understanding of supporting families in the different phases of cancer are poorly described.

To date, the examination of nurses in relation to caring for patients with cancer has primarily focused on the experience in palliative care (Jezewski & Finnell 1998, Tarzian 2000, Volker 2001). There is limited work in other cancer settings, such as more active treatment scenarios. To date, no research has been found on the experience of nurses caring for patients receiving active/curative treatment for recurrent cancer. It is surprising, then, that cancer researchers, who often emphasise the importance of giving voice to people who are facing a phenomenon (Polit & Beck 2004), have forgotten to give voice to the nurses involved in the care of patients and families living with a recurrence of cancer. This is even more surprising when there is strong evidence suggesting that caring for people living with cancer may be particularly stressful for nurses (De Carvalho *et al.* 2005, Escot *et al.* 2001, Isikhan *et al.* 2004, Main 2002, Omdahl & O'Donnell 1999, Penson *et al.* 2005,

Quinn 2003). That is why one of the aims of the current research is to fill this gap by exploring nurses' experiences of caring in the recurrent phase of cancer.

FAMILY NURSING AND CANCER CARE

With an understanding of the salient aspects of the experience of suffering in patients and families, and the experience of nurses involved in the care for these families, we are in the position to consider what the most useful approach to deal with family suffering will be. This section will not present such approaches but chapter 7 will propose nursing interventions to help families deal with suffering in cancer recurrence. Rather, the aim of this section is to show that family nursing is a possibility in a family-based approach to cancer nursing.

The interest in the family is not exclusive to health sciences but it has been also a research interest for many others, including sociologists, economists, and anthropologists. In nursing in the sixties, theorists began to clarify nursing practice and to articulate the philosophy and aims of nursing care. Initially, theorists were concerned only with individuals but gradually these became viewed as part of larger social systems such as the family. Although theorists' models did not discuss the family as such, some models, such as Orem's, showed that nursing should be concerned with families. In the seventies and eighties, theorists such as Orem, King, Roy, Rogers, and Newman included the family concept within their work (Hanson *et al.* 1997). Although the idea of care for families has existed since the 1970s, it was only in the early eighties that the two ideas were combined and the concept of family nursing came to the fore (Friedman *et al.* 2003). Family nursing is still relatively young, but Friedman (2003) argues that there is strong evidence that the distinct nursing speciality is growing in practice, education, and research. The concept has been applied to paediatric nursing and community nursing particularly (Friedman 1989, Rennick 1995). However, significant progress is being made in expanding family nursing in cancer research and practice (Moore *et al.* 2005).

In recent years, the concept of family-centred care has emerged, bringing confusion into what family nursing and family-centred care actually means, and in what sense the two concepts differs. A concept analysis study throws light on the meaning of family-centred care as related to a holistic approach that supports parental involvement and participation in children's nursing (Hutchfield 1999). This creates the potential for the development of strong associations with parents and nurses that appears to be a central element in the care of children. However, the practice of family nursing has a broader interest and includes the provision of care to families and family members in health and illness situations, no matter the family development stage.

The interest of family nursing lies in viewing the individual holistically. The person is more than biology; s/he is a unity of physical, psychological, spiritual, and social spheres that are in constant interaction with other people (Hanson *et al.* 1997). In particular, the family is the basic unit of this social interaction. In a health context, this implies that when a member of a family falls ill, stress experienced by any member of the family unit is transmitted to all members of the unit (as described earlier in the experience of cancer). According to Hanson (1987), the purpose of family nursing is:

to promote, maintain, and restore family health: it is concerned with the interaction between the family and society and among the family and individual family members (p. 8).

Hanson's definition seems one of the most appropriate as it shows that family nursing not only focuses on health problems, but also on others aspects of the life cycle that require new adaptation. Family nurses do not only work with dysfunctional families but are "commonly involved with families experiencing situational or developmental transition in their family life cycle. These transitions may be voluntary or involuntary, planned or spontaneous" (Hanson, 1987, p. 7). This statement is shared by Whyte (1997) who recognised that the whole philosophy of family nursing is about working with families and helping them to recognise their

problems and mobilise their own coping resources in order to be able to master a perceived threatening situation.

Of importance then, is that health care professionals address the needs of the family, involving the patient and the family members' needs, through a family-level service (Friedman *et al* 2003). Consideration of the practice of family nursing in relation to family assessment and intervention will be discussed in chapter 7 through presentation of the data that emerged from the current study.

Summary

Despite increasing awareness of the impact of chronic disease on the family, less attention has been paid to the impact of cancer on the family. Studies have generally examined the burden of cancer for caregivers, but limited understanding exists of the impact of cancer on the family system wellbeing. The literature presents a perspective that family members are observers rather than actors (Lynam 1995). Less information is available about the psychosocial experience of recurrence for the family. For the most part, research has focused on spouses/partners of women with breast and ovarian cancers. Certainly, this research is valuable to increase the understanding of the impact of recurrence on families. Nevertheless, it is important to understand the experience of families living with other types of cancers because each cancer has its particular concerns.

However, if nurses are to establish evidence for the development of interventions to improve care, we first must comprehend more clearly the specific issues patients and family members experience during the cancer phase of recurrence. Because the patient, the family member, and the nurse are involved in the cancer trajectory, this social interaction is researched in this study as a method for interpreting the psychosocial impact of recurrence of cancer. In addition to understanding the experience of family suffering in recurrence, nurses need to recognise their daily experience of caring for these families and their interpretation of recurrence in order

to know how such experiences and meanings are translated into nursing practice. It is from this psychosocial perspective that the current study will explore the views of patients, family members, and nurses as they deal with the crisis of cancer recurrence.

CHAPTER 3

RESEARCH METHODOLOGY AND PROCEDURES

Introduction

One of the most important aspects in research is the development of a clear and well thought out research proposal. Developing a research design is a systematic process that requires time, intellectual endeavour, and planning if the aim is to produce accurate findings (Vivar *et al.* in press). A research design needs to provide information about who, what, where, when, and how of the subjects under study. The current chapter outlines the design of this grounded theory study placing emphasis on the development of the research and reasons for the choices that had been made. The chapter explains the paradigms selected to explore the psychosocial nature of cancer recurrence, research methods, the process to gain approval to conduct the study, the collection of data and its interpretation, aspects related to rigour and accuracy of the findings, and the ethical considerations required in this study.

Grounded theory

POSITIVISM VERSUS INTERPRETIVISM

There has been constant debate on the value of quantitative and qualitative research in the world of science (Krantz 1995, Shadish 1995). The main reason for this debate derives from the differences between the qualitative and quantitative paradigms, which are briefly presented here. Conflict between the two types of research arises when one methodology adopts an approach of superiority over the other. It is important to highlight that the fact that there is diversity between the two paradigms

does not imply that one is superior to the other. On the contrary, each generates a different but complementary type of knowledge (Kelle & Erzberger 2004, Sechrest & Sidani 1995). The most important consideration is that the choice of the paradigm emerges from the purpose of the study (Crotty 1998, Parahoo 1997, Silverman 2000). In other words, the nature of the phenomenon being studied determines the methodology to be used.

Quantitative research, based on natural sciences, aims to quantify information (Robson 2002). Quantitative research, relying on deductive logic, is characterised by its scientific nature which determines the rigorous nature of the research (Neuman 2003). Interest is focused on what is general and representative, so that statistical generalisation and prediction can be reported. There are two types of quantitative studies aiming at quantifying relationships. These are observational studies, attempting to measure variables without changing behaviours or conditions, and experimental studies, focusing on the measurement of variables before and after intervention (Neuman 2003). On the other hand, qualitative research, which has its origins in sociology, aims to emphasise the dynamic, holistic, and individual aspects of the human experience and it attempts to capture those aspects in their entirety, within the context of those who are experiencing them (Silverman 2000). In a family context, qualitative research contributes to understanding the meanings and subjective experiences of family members. That is why it has traditionally been used to capture family life events and processes (Handel 1992). Contrary to quantitative design which involves a rigorous and controlled design, qualitative research uses flexible research design that allows for changes during data collection (Polit & Beck 2004). This fact appears of relevance when exploring family concerns, as changes in the initial design may enable obtaining “truer” contextual family data (Gilgun *et al.* 1992). According to Creswell (1998), qualitative research is often used when variables cannot be easily identified, theories are not available to explain the behaviour of participants, and theories need to be developed.

The purpose of this research is not to investigate prediction and control the phenomenon of cancer recurrence, as a quantitative approach would do. Rather, it is

to study the phenomenon from the reality of participants. In the present study, conducting a quantitative study would allow the researcher to describe the experiences related to one or various demographical and social variables using predetermined measures. However, the findings from a quantitative approach would fail to explore the experiences of cancer recurrence from the perspectives of patients, family members, and nurses. As mentioned earlier, there are health problems that cannot be dealt with using a quantitative paradigm, and must be addressed using a qualitative approach that permits exploration of complex human experiences (Mira *et al.* 2004, Patton 2002, Schwandt 1994, Silverman 2000). Therefore, a qualitative approach contributing to a multi-perspective understanding of the social meaning of cancer recurrence is considered a valid alternative for the purpose of this study.

RATIONALE FOR USING GROUNDED THEORY

Grounded theory, which was originally developed to study the experience of dying, is a method used in qualitative research for investigating social phenomena in natural settings (Glaser & Strauss 1967). Grounded theory has been used widely in Social Sciences as a means to develop theories about the social and psychological processes of individuals undergoing major life changes, such as chronic illnesses (Conrad & Bury 1997, Woog 1992), family processes (Lewis & Deal 1995, Murphy 1992), and nursing interventions (Corbin & Strauss 1992, Schumacher 1996). Indeed, grounded theory at first evolved mainly in the area of nursing, where Glaser and Strauss themselves had initially applied it. In the context of this nursing research, grounded theory has been identified appropriate to the purpose of this research.

THE INDUCTIVE APPROACH IN GROUNDED THEORY

Grounded theory is a well-established research methodology that aims to describe the basic social processes together with the context and conditions, and generate a substantive theory that explains the phenomena under study (Glaser & Strauss 1967).

Grounded theory is designed to generate theory from empirical data, rather than validate existing theory (Reichertz 2004, Strauss & Corbin 1998). This approach is known as analytical induction, also called inductive reasoning (Polit & Beck 2004). As an inductive paradigm, grounded theory used induction as a cognitive process to collect data, develop analysis, and organise the findings. The analytical induction is based on interpreting data from specific observations to general rules in order to generate hypothesis (see Figure 2). This analytical approach is a common strategy for analysing qualitative data (Creswell 1998). Grounded theory analysis is inductive, in that the resulting theory emerges from the data through a process of rigorous and organised analysis (Böhm 2004, Charmaz 2003, Chiovitti 2003, Cutcliffe 2000).

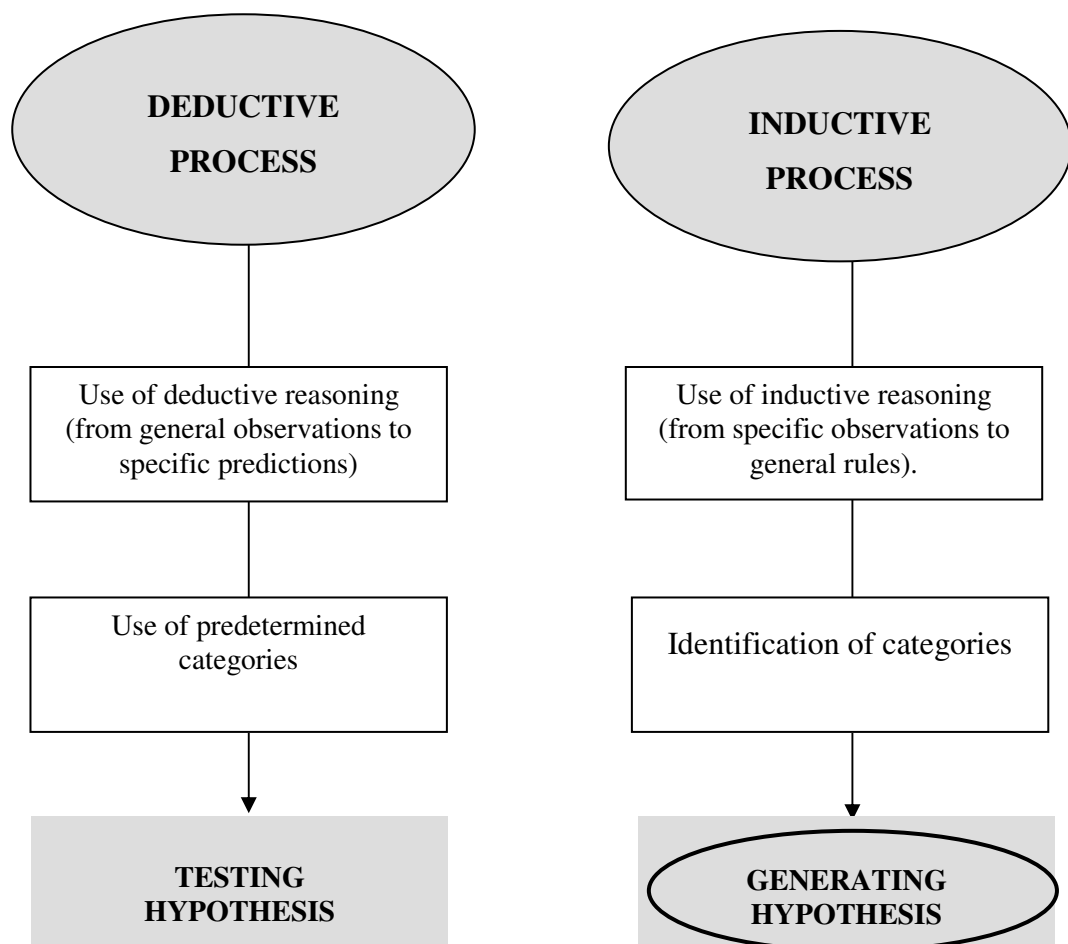


Fig 2. Differential characteristics between the deductive and inductive process (based on data from Charmaz 2006, Polit & Beck 2004, Reichertz 2004)

THE METHODOLOGY OF GROUNDED THEORY

There are several reasons for the rationale of using grounded theory as a research methodology. Some authors have suggested that using grounded theory is well suited to exploring unknown situations (Smith & Biley 1997, Strauss & Corbin 1998). Besides, the aim of using grounded theory is to understand the nature of human behaviour by generating theories about social and psychological phenomena (Chenitz & Swanson 1986). Discussion in the introduction of this thesis showed that previous studies have failed to fully delineate perceptions of cancer recurrence from the viewpoint of families and professionals. There has been little investigation into the phenomenon of recurrence from a psychosocial perspective and little knowledge is available in scientific literature. Others have noted that grounded theory is often used to explore processes of transition and change (Creswell, 1998). The use of grounded theory is considered pertinent in this study because cancer recurrence has been described as a transition (Cella *et al.* 1990, Rawnsley 1994). In addition, the sociologists Glaser and Strauss (1967) who discovered grounded theory pointed out that the methodology was adequate when the aim of the research was to develop a theory that shed light on human behaviour and the social world (p. 3). Since the purpose of this research is to gain understanding which will contribute to the development of a theoretical framework for family nursing in oncology, a grounded theory approach is deemed appropriate to enable a substantive theory to be developed from data. This might add a new psychosocial perspective of cancer recurrence.

Another important aspect of the research methodology is that the specific aims and research questions drive the approach and method to be used (Denzin & Lincoln 2003). In the current study, there is a correspondence between the methodology and the research purpose, which guides the study in its exploration of the social construction of cancer recurrence.

THEORETICAL FRAMEWORK

Grounded theory is based on symbolic interactionism, which permits understanding of how individuals define a phenomenon via their social interaction (Blumer 1969). In grounded theory, reality is socially and culturally based and the aim of using the methodology is to understand human behaviour by generating theories derived from empirical data (Strauss & Corbin 1990). Consequently, there is no attempt to use a theoretical framework that guides research for theory testing (Chenitz & Swanson 1986). However, the fact that grounded theory does not use a theoretical framework does not mean that the researcher does not have a perspective to follow. Indeed, the theory of symbolic interactionism underpins grounded theory (Strauss & Corbin, 1990). Symbolic interactionism focuses on the meanings given to events by the people involved (Blumer 1969). Three central assumptions rest on symbolic interactionism (Blumer 1969, p. 2):

- human beings react to things on the basis of the meanings that things have for them.
- meanings are derived from social interactions with individuals.
- meanings are created and modified by an interpretative process used by the person concerned.

According to Blumer (1969), symbolic interactionism views individuals as social actors whose experiences and beliefs are influenced by who they are and by what role they play within their environments. A central aspect behind symbolic interactionism is that the theory is primarily interested in the study of the life of a human group, and stresses the interactive processes that occur in social relationships (Denzin 2004). It is then in social interaction that individuals become a rational being and, through social interaction, they develop the meanings of events.

Using this perspective, grounded theory provides a means of investigating human behaviour, developing a new understanding of common social behaviour (Denzin 2004). In other words, symbolic interactionism guides grounded theorists in

understanding the meaning that individuals assign to events (Baker *et al.* 1992). Cancer recurrence as a symbol has meanings for individuals (Mahon & Casperson 1997). Interestingly, using symbolic interactionism was found appropriate as an approach to family research (Stryker 1967). In a chronic condition, such as cancer, there is continued interaction between patients and their family members as well as with healthcare services (Baider *et al.* 2000). The interaction between the triad of social actors of patients, family members, and professionals has been named *the therapeutic triangle in healthcare* (Hanson & Boyd 1996). For the above-mentioned reasons, I found symbolic interaction orientation acceptable as a means of studying the significance of cancer recurrence from the perspectives of patients, families, and nurses.

In summary, grounded theory was chosen for its explanatory focus when little is known, its contribution to theory generation, the way it fits in with the research purpose, its flexibility and rigour as a qualitative approach, and its foundation on social interaction. In addition to the rationale for using grounded theory in this study, it seems important to elucidate the ongoing debate about the use of this methodology. The next section briefly will deal with this issue.

DIVERGENCES IN GROUNDED THEORY

The methodology has not escaped critics since Glaser and Strauss first proposed it in 1967. Various discrepancies have been identified within literature. For instance, researchers refer to grounded theory in different ways. Some view grounded theory as a methodology (Keddy *et al.* 1996) whereas others take it as a method (Pandit 1996). What is of importance is that researchers explain what they mean by methods and methodology. According to Crotty (1998), methods are “the techniques or procedures used to gather and analyse data related to some research question or hypothesis” (p. 3). Methodology, however, refers to “the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes” (Crotty 1998, p. 3). This

clarification supports that grounded theory is a methodology that has its methods of preference, of which interviews are often used (Wimpenny & Gass 2000). The methodology requires the investigator to interpret meanings, experiences, events, and social realities for deeper understanding of social phenomena (Backman & Kyngäs 1999). This analytical work is particularly intense for novice grounded theorists because the methodology has been said to demand a painstakingly precise method of study that requires high levels of experience and skills on the part of the researcher (Allan 2003).

Others discrepancies in the understanding of grounded theory refer to its epistemology, that is the ways of understanding and explaining the world. Some identify grounded theory as an interpretative style of qualitative research in the post-positivist paradigm, in that the processes and outcomes are not judged on the basis of traditional scientific criteria (Denzin & Lincoln 1994). In a more recent view, grounded theory is located within the constructivist paradigm (Charmaz 2003, Charmaz 2006). Wilson and Hutchinson criticised grounded theory emphatically by identifying a set of methodological mistakes which compromise the bases of the qualitative methodology (Wilson & Hutchinson 1996). Even the co-originators of grounded theory differ in their more recent, separated texts (Glaser 1992, Glaser 1998, Strauss & Corbin 1990, Strauss & Corbin 1998). The differing opinions of Glaser and Strauss are well documented in a study that compared grounded theory approaches in relation to issues of induction-deduction, ways of analysing data, and format of theory generation (Heath & Cowley 2004). Another paper distinguished the reasons and points of divergence between Glaser and Strauss's applications of the grounded theory approach, with an attempt to show the salient points in applying grounded theory in nursing research for novice users of this methodology (Boychuk-Duchscher & Morgan 2004). In the publication of *Rediscovering Glaser*, Melia (1996) shed some light on the difference of opinion between Glaser and Strauss and she concluded by hoping that this debate will only "join the ranks of academic differences of opinion and ultimately will not damage the larger enterprise that was launched with *The Discovery of Grounded Theory*" (Melia 1996, p. 378).

In this research, rather than debating about the variants of grounded theory, I focused on developing my own understanding of grounded theory by doing it, and by critically selecting a grounded theory process that best contributed to rigorous construction of an understanding of the phenomenon of cancer recurrence. For this, I used various texts, including the original manuscript of *The Discovery of Grounded Theory* (Glaser & Strauss 1967), the more recent text by Strauss and Corbin, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (Strauss & Corbin 1998), and a practical guide recently published entitled *Constructing Grounded Theory* (Charmaz 2006).

Research methods

The methods used in qualitative research have been criticised as producing mere description and anecdotal evidence (McLeod 2001). Nonetheless, qualitative data are important to show participant's own life experience (Miles & Huberman 1994). Qualitative researchers often make use of multiple methods such as interviews and observation in an effort to understand the complex milieu of the phenomenon under study (Streubert & Carpenter 1995). The choice of using different methods has been also highlighted in family research (Gilgun 1992). One of the most common methods used in grounded theory is interview (Wimpenny & Gass 2000). However, an important characteristic in the selection of qualitative methods is that the aim of the study determines which methods of data collection are most appropriate (Ästedt-Kurki & Hopia 1996). In view of the above and since the aim of this study is to explore families' and nurses' experiences of recurrence of cancer, it was decided that qualitative interviewing would be used as the means of data collection for the current study. A combination of different sources of data, which is one way of ensuring thoroughness in qualitative research (Flick 2004, Moran-Ellis *et al.* 2006, Tobin & Begley 2004), was deemed suitable for the study.

TRIANGULATION OF SOURCES OF DATA

Triangulation is a relatively new concept in Social Sciences. First used in the military and navigation sciences, triangulation was introduced as a synonym for convergent validation in the description of a “multitrait-multimethod matrix” (Campbell & Fiske 1959). That is, triangulation was a term used to plot positions from several points. Later, social researchers refined the concept as mixing qualitative and quantitative methodologies and indicating that both should be used as complementary methodologies rather than rivals (Creswell 1998, Denzin 1978, Flick 2004, Jick 1979, Moran-Ellis *et al.* 2006). In qualitative research, triangulation has gained wide acceptance as a means of validating and confirming findings (Flick 2004). In nursing, triangulation has been also used to obtain methodological thoroughness (Tobin & Begley 2004).

The procedures suggested by triangulation are various. Denzin (1978) distinguished four types of triangulation: by data source, by research method, by researcher, and by theory. Triangulation by data source consists of combining more than one source of data in a study to obtain full information from a variety of sources. For example, data can be obtained from patients, providers, family members, literature, newspapers, or textbooks. Triangulation by research method entails the use of more than one method in a study. This can be by combining different qualitative methods or a combination of qualitative and quantitative procedures. For example, a variety of methods can be used, such as focus group, formal interview, informal interview, observation, and survey. Another way to triangulate is when various researchers perform data collection and data analysis independently. Finally, triangulation by theory consists of interpreting data by combining different theoretical frameworks (Denzin 1978).

In line with the differing types of triangulation, I decided to follow the technique of triangulation of sources of data in order to gain a comprehensive picture of the participants' experiences of cancer recurrence. The sources of data included: patients, family members, nurses, memos, and literature (see Fig 2). Glaser and Strauss (1967) stressed the virtues of collecting data from a variety of sources, both

to enhance variation in the data and confirm emergent categories. Further aspects of triangulation related to thoroughness are discussed later in this chapter.

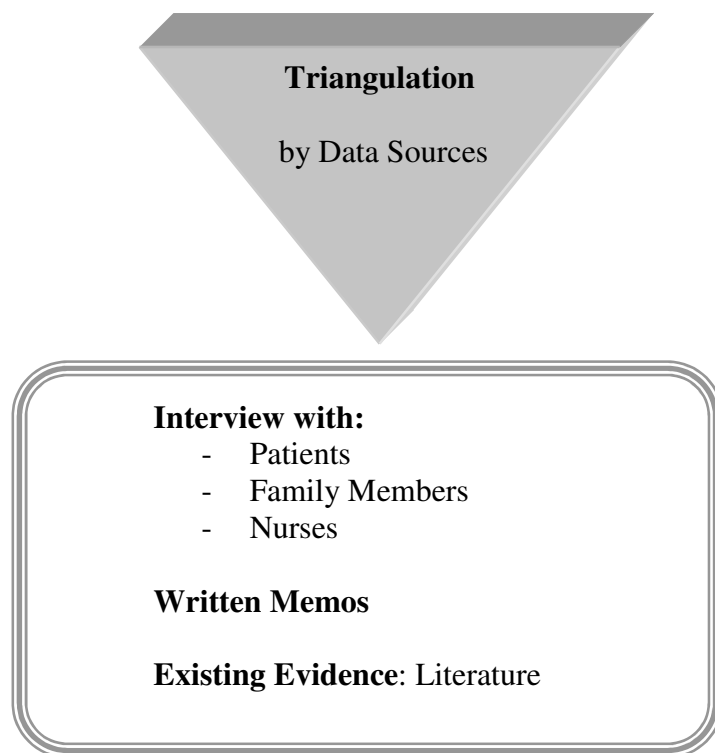


Figure 3. Triangulation of sources of data

FAMILY INTERVIEW

The challenge of providing a holistic view of families living with a recurrence of cancer can be met by interviewing different groups of people, involving patients with recurrent cancer, their family members, and nurses. Together, these sources of data will provide a different but complementary view of the phenomenon of recurrence. Conducting qualitative interviews allows us to obtain descriptions of the world of the

interviewees with respect to their interpretations of the meaning of the described phenomena (Rubin & Rubin 1995). In this research, using open interviews would permit us to gain subjective descriptions of patients', families', and nurses' experiences of cancer recurrence. Besides, interviews have been identified as a research method that allows interviewers to develop a rapport with interviewees (Prenee & Douglas 1999). This fact may give participants the opportunity to express fears and concerns during the interviews, and possibly to discuss aspects that they might not have mentioned to anyone else before.

A question arose as to what a family interview was and how many family members should be included within the research. There are different views within literature on this matter. Some researchers take the individual as the unit and explore individual's experiences and behaviours. Others, however, identify the importance of accommodating multiple family perspectives to allow richer accounts of family processes. In this line, Ästedt-Kurki and Hopia (1996) defined family interview as "a method of data collection where all members of the family unit are involved in a group setting specially designed for the purpose of gathering information" (p. 507). This definition limits the utility of family interview because simultaneous interviewing of the family as a unit is complex due to lack of human and material resources. To date, much of the research pertaining to families living with cancer recurrence has focused on the impact of illness on individual family members, usually the husband of women with breast cancer. No nursing study has been found which includes all family members as interviewees. This may be due to the difficulty, if not impossibility, of studying the family unit in some areas of care, such as during hospitalisation. However, there are other forms of family interview. Researchers have the choice of interviewing various family members simultaneously or at different times (Ästedt-Kurki *et al.* 2001). This type of family interview provides a composite family picture, as data comes from different sources.

Initially, I considered interviewing multiple family members simultaneously or at different times. I thought this was possible because the research was conducted in Spain, where families usually accompany their ill relative during hospitalisation

(Quero Rufián *et al.* 2005, Rodriguez-Martinez *et al.* 2003). Medical units are open to families, allowing them to stay at the bedside and to sleep over. Since I planned to conduct the study during ambulatory or conventional hospitalisation, it was deemed possible to recruit a patient in treatment for recurrent cancer, the primary caregiver within the family, and another family member who accompanied the patient. Listening to these three voices was believed to contribute to a holistic view of families with a recurrence of cancer. However, while in the natural setting, I observed that many patients were accompanied by only one of their family members. This can be explained by the fact that the patients were often from different regions of Spain, and this might limit travel of various members. Given this situation, and although I initially planned to conduct interviews with two family members of a same patient, I decided to include patients who were accompanied by one relative only. In reaching this decision, I considered that this approach would also elicit rich descriptions of the experience of cancer recurrence from the perspective of families.

An important issue requiring special attention referred to disclosure of diagnosis and prognosis. Cross-cultural issues in the disclosure of cancer have been documented (Mitchell 1998). Surveys in different European countries, including Spain, have found cultural differences in the rates of disclosure of a cancer diagnosis or prognosis (Espinosa *et al.* 1993, Estape *et al.* 1992). Taking into consideration the fact that patients or family members may hide their emotions and beliefs to protect their relative(s), it seemed pertinent to separate patients and family members in order to allow participants to tell their experiences simultaneously. However, the families who communicated their preferences to be interviewed at the same time (because they felt more comfortable if they were together) would have this opportunity. This decision was taken because participants' wellbeing took priority over the interests of this research.

THEORETICAL SAMPLE

Theoretical sampling is concerned with the selection of participants on theoretical grounds in order to explore categories emerging from data and to develop, explain, and test theory as data analysis progresses (Mason 1996). Theoretical sampling is used to guide the construction of a theory by checking and refining emerging conceptual categories (Strauss & Corbin 1998). It is not a sampling procedure for representativeness of a certain population, but is helpful in facilitating the testing, development and refinement of emerging categories (Charmaz 2006). Because the purpose of the current research was to discover a theory grounded in data that explained the basic social processes of cancer recurrence, a theoretical sampling was selected for this study (Glaser & Strauss 1967). This procedure dictates that specific people should be asked subsequent questions about specific incidents, with the aim of saturating the nature of concepts and ensuring adequate relationship between categories (Chenitz & Swanson 1986). Given this, theoretical sampling was deemed appropriate for this study because it would ensure that the evolving analysis drove the selection of key incidents and the identification of key participants relevant to the emerging theory.

To maximise variability among participants, a maximum variation sampling, which is a theoretical sampling approach that involves the selection of cases with a wide range of variation, was chosen (Polit & Beck 2004). A maximum variation sample, in which all patients were at the recurrent stage of cancer but with different cancer diagnoses and a wide range of ages, was selected for two main reasons. Firstly, as most of the literature on cancer families has focused on women with breast cancer, recruiting respondents with different cancer diagnoses and a composite of ages would contribute to a full range of psychosocial problems in people living with cancer recurrence. Besides, approaching participants from a variety of backgrounds would allow me to find the common ground between people, enabling theoretical understanding.

Conducting a theoretical sampling process involves the selection of the initial participants using a purposive technique (Baker *et al.* 1992, Coyne 1997). At the beginning of the study, I selected people who I believed would maximise the possibilities of obtaining a full coverage of data. Participants who met the inclusion criteria and who were admitted to the selected units were recruited. After data collection and analysis of the initial data, the sample became more selective. The selection of new participants was guided according to the emerging codes and categories, as guided by the theorists Glaser and Strauss (1967). Sampling changed to theoretical and participants were recruited according to the needs of the developing theory. Theoretical sampling was conducted concurrently with data analysis through the research process. To fully describe the experience of a cancer recurrence, patients who were at different stages of their cancer treatment were interviewed.

CRITERIA OF INCLUSION FOR PATIENTS

In this research, patients who received a diagnosis of recurrent cancer and who met the following criteria of inclusion were considered for the research:

- a) Being diagnosed with recurrent cancer (first, second, third, or further recurrence).
- b) Being informed of the diagnosis of recurrence.
- c) Having been in remission for a period of at least 6 months after the end of treatment.
- d) Undergoing active treatment for recurrent cancer.
- e) Having a life expectancy of more than 6 months at the time of recurrence.

f) Being over 18 years old.

Justification of the selected criteria of inclusion is presented. Regarding a), it has been noted that distress is linked with degree of disability and sickness rather than site (Weisman & Worden 1986). With reference to this point, interest was paid to the phenomenon of cancer recurrence as a psychosocial event rather than to a medical perspective. Including patients with different cancer diagnoses and at different stages of their recurrence was deemed appropriate to the aim of this research. In addition, recruiting patients with a variety of circumstances might contribute to the transferability of the findings, as I will explain in the final section of this chapter.

In relation to b), because of the rights of patients to not being fully informed of their disease if they so wish, I considered it unethical to introduce information that might cause distress and discomfort for the patients by asking them about their experiences of having recurrent cancer. Therefore, no patient was approached unless one of the staff, a physician or nurse in charge of the patient, confirmed that the patient was informed of the diagnosis.

In relation to c), the fact that all patients were in remission justified the goal of this research that was to explore the phenomenon of recurrence; recurrence meaning when cancer has returned after a period of time during which the cancer could not be detected (National Cancer Institute 2006). This meant that the patients had survived for a period of at least 6 months without evidence of the disease. Therefore, the patients might be short-term survivors (they might have been cancer-free from 6 months after the end of treatment to 5 years) or long-term survivors (cancer-free for at least 5 years).

Regarding d), the fact that all patients were undergoing active cancer treatment narrowed the study, since the selected participants was a group with reasonably good-short-term prognosis. However, I considered that important information could be obtained on the matter by interviewing the patients and their relatives while they

were actively engaged in coping with psychological impact of relapse and treatment for recurrent cancer.

Concerning e), it has been defined that a patient whose life expectancy is lower than 6 months is considered a terminal patient. Patients who were transferred into palliative care were excluded from the study because they were likely to be coping with the terminal phase of cancer. In addition, as discussed in the introduction of this thesis, most of the available literature on cancer has focused on the initial diagnosis and the end of life. Given this, it was deemed important to add new knowledge on the specific recurrent phase of cancer by only including patients at this stage of the cancer trajectory. Information about whether a patient had a life expectancy over 6 months was determined by consultation with the nurse in charge of the patient. If the nurse did not know the data, I consulted the physicians on the unit who assessed the estimated life expectancy of the patient.

Finally, with regards to f), section 12 of the Spanish Constitution has fixed the age of majority at 18 years (Constitución Española 2005). In the Spanish political and cultural environment reaching the age of majority determines the possibility of persons to exercise their rights and obligations within society. Hence, it was decided to only include people who, in political terms, have the capacity to act and decide freely. Age is also a criterion of concern because the results of the research are directed toward adult cancer nursing, paediatric nursing being excluded. The nurse in charge informed me of the age of patients.

The exclusion criterion was that the patients were too distressed to participate in the study either because they were too ill due to side effects of treatment or because they were psychologically distressed.

CRITERIA OF INCLUSION FOR FAMILY MEMBERS

Patients guided the selection of family members. In that sense, there were no predetermined criteria for inclusion solely that family members were:

- a) Identified by the patient as a family member.
- b) Accompanying the patient during inpatient or outpatient stay for cancer treatment.
- c) Over 18 years old.
- d) Willing to be included in the study.

In relation to a), family members were individuals who accompanied the patient through the cancer trajectory and who were mutually identified by the patient and by themselves as members of the family.

Regarding b), if family members were accompanying their ill relative, it would be more probable that relatives were informed of the patient's disease and thus they could discuss their experiences of cancer recurrence. In addition, it was deemed feasible that relatives who came with patients during treatment would have the capacity to express their perceptions of nursing care.

In relation to c), young and adolescent family members were excluded because of legal aspects, as previously described for patients. Consideration was also given to ethical issues. It was anticipated that disclosure of complete information could be hidden from the youngest family members in order to avoid intense emotional suffering.

CRITERIA OF INCLUSION FOR NURSES

The criterion for the selection of nurses was that they were in possession of a diploma in nursing. Since all Spanish nurses require a nursing diploma to be able to practice their profession, no difficulty was found in that respect. In addition, nurses should be working in the units that were selected for this research.

SAMPLE SIZE

A major concern in qualitative research is the number of subjects needed in a sample. Qualitative research does not require a large number of participants because its aim is not to generalise the results to a broader population, but rather to contribute to the experience of a small number of individuals who have experienced the phenomenon of interest (Polit & Beck 2004). According to Creswell (1998), interviews with 20 to 30 participants are a reasonable sample size in most qualitative research. Polit and Hungler (1995, p. 299) reported grounded theory studies use to be based on samples of 20 to 40 participants). Others have argued rationally that in grounded theory the researcher cannot accurately anticipate the number of participants required for the study because the sample size is a matter of theoretical saturation (Strauss & Corbin 1998). That is, sampling continues until categories do not provide new concepts of importance for the theory development. Therefore, it is the researcher's decision to stop collecting data when further sampling fails to reveal additional categories or interrelationships. In this research, saturation of data occurred after conducting 15 family interviews and 14 interviews with nurses. Details about theoretical sampling process have been presented earlier.

Research context

Since grounded theory seeks to generate theory about a social process, the research has to fit in with the social setting (Glaser & Strauss 1967). In an attempt to enhance the validity of the study, I designed the research to be performed in two different centres. This might also contribute to a wide variation of data, helping the theory to develop (Strauss & Corbin 1998).

A private University Clinic and a Public Hospital, both specialised in cancer care and located in different regions of the North of Spain, were initially selected for this research. Approvals from the University Clinic were obtained. However, access to the Public Hospital was denied, arguing that there were various studies being

conducted at that time in the oncology department. Accordingly, I asked for approvals in another main hospital and consent was obtained. Finally, two hospital centres located in the same city in the North of Spain were selected to conduct this research. These two centres were approached because they are two of the reference hospitals in cancer care in the region. Although one of the selected centres was private, it was not the aim of this research to compare results between the private and public sectors. However, I acknowledged that differences in responses between the two centres might emerge. To shed light on potential differences that would be relevant in the interpretation of the findings, I anticipated documenting differences in the writing-up of this thesis.

Regarding the selection of settings, I initially decided to interview patients who were hospitalised in an oncology unit. This meant that a patient was admitted to hospital as an inpatient, so length of stay was not too short, and I could have time to approach the participants. However, once in the natural setting, I realised that a wide number of patients treated for cancer recurrence were receiving ambulatory treatment, on an outpatient basis. Therefore, after talking with two expert oncology nurses about the benefit of including outpatients in this research, I decided to approach both inpatients and outpatients. This would contribute to a wider description of the experience of cancer recurrence, allowing the theory to emerge from a variety of data. A multi-site study was then deemed valid to the aim of this study.

Four different settings were selected from the two hospitals. An oncology day unit, an oncology week-unit, and an inpatient unit were selected from the private sector and an oncology day unit from the public sector (see Figure 4). This variety of settings permitted inclusion of patients with a longer or shorter hospital stays, which ensured that the emerging theory was located in a broad body of knowledge. The fact that participants were identified in different settings also allowed me to gather context-specific information regarding cancer recurrence, as Creswell (1998) noted in his work.

In the four units, registered nurses (specialised and non-specialised in cancer nursing) cared for cancer patients. Details of the nurses will be presented in a later section.

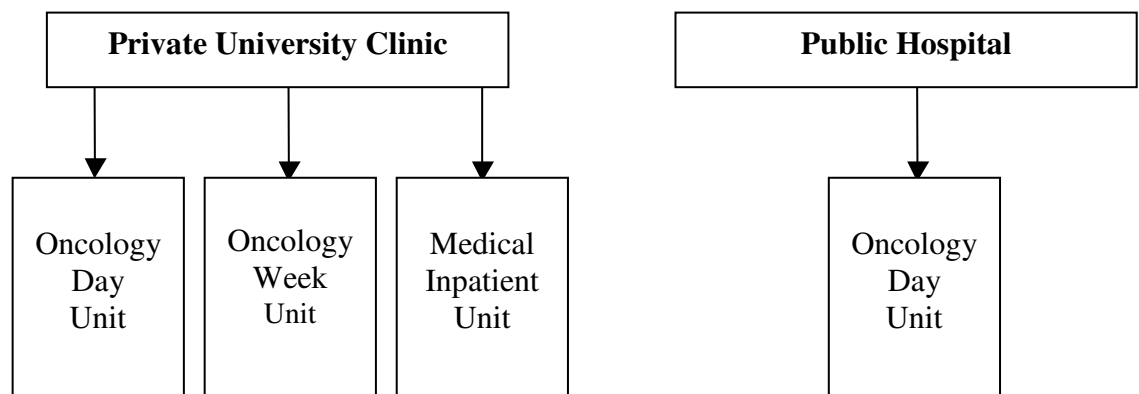


Figure 4. Selected settings

CHARACTERISTICS OF THE SETTINGS

Oncology Day Unit in the University Clinic - A total of 6 nurses worked in the unit which had a capacity of 15 beds. The service was open from Monday to Friday from 9 am to 9 pm and on Saturday mornings. Patients were admitted to receive cancer treatment for a short period, which ranged from 30 minutes to some hours. In this unit, patients were in single rooms, which fact allowed their family to be with them during chemotherapy treatment.

Oncology Week Unit in the University Clinic - This unit provided a broad range of cancer therapies in a week ward setting. A total of 9 nurses worked in the unit which had a capacity of 20 beds. The service was a new outpatient unit where patients were hospitalised to receive treatment and cancer care. The unit was open from Monday to

Saturday afternoon and other wards in the clinic provided an out-of-hours service. A staff nurse in collaboration with oncologists assumed care of each patients.

Medical Inpatient Unit in the University Clinic - A total of 9 nurses worked in the unit which had a capacity of 20 beds. The service was a conventional unit of hospitalisation where patients with medical problems or oncology problems were hospitalised. The unit was open 24 hours from Monday to Sunday. Nurses provided care for cancer patients from diagnosis to final stages of the disease, including the dying process.

Oncology Day Unit in the Hospital - A total of 6 nurses worked in the unit which has a capacity of 12 seats. The unit was open from Monday to Friday from 8 am to 9 pm. This unit consisted of two main areas: a main treatment room having 10 functional recliner chairs that were separated by curtains to allow privacy during treatment; and two separate treatment rooms with 1 bed in each room for delicate patients.

In the four units, nurses dealt with the safety of patients and family members during treatment, and patient/family education and support.

Collecting data

INTERVIEWS

INTERVIEWS WITH PATIENTS AND FAMILY MEMBERS

I started contact with families and nurses in the University Clinic. Patients who met the inclusion criteria and who were thought to contribute to rich descriptions of their experience of a cancer recurrence were selected. The way patients were identified in the different settings was negotiated with the nurse manager of each of the units, according to the structure and organisation of the settings. In the Oncology Week Unit, the nurse-manager identified potential participants whereas in the two other settings it was the nurses who identified possible participants. Once the nurses

identified participants, I spoke with the nurse in charge to determine if the patients met the inclusion criteria. If any doubt arose, the nurse reviewed the medical history of the patient. If the nurse did not have the required information, I consulted the doctor on the unit.

After conducting 29 interviews (10 with patients, 10 with relatives, and 9 with nurses) in the University Clinic, I started data collection in the Public Hospital. Both an oncologist and a cancer nurse identified suitable patients. When they identified potentially eligible participants based on the inclusion criteria given in writing to them, they informed the patients of the ongoing study. If the patients indicated initial willingness to participate, I was introduced to the eligible patients and their family members, if they were present. Written informed consent and an information sheet (as well as verbal information) were presented to interviewees. A separate time for the interviews with the patient and the family member was arranged. However, if interviewees reported their wish to conduct a simultaneous interview, I accepted (as I will explain in the section on ethics).

To recruit participants, I visited each ward twice a week during the initial collection of data and asked nurses if new patients with cancer recurrence had been hospitalised. Moreover, information of new patient arrivals was sometimes reported via electronic messages and telephone calls. Approaching family members was generally easy because most of the time they were with the patient. Therefore, I asked the relatives who were with the patient if they were willing to participate.

During contacts with patients and relatives, I spent time talking with them to gain their trust and rapport. I presented written and verbal information about the study, development of the interviews and involvement of relatives. In addition, I made sure of informing them of the following points:

- ✓ I was a nurse doing research on the experience of patients, family members, and nurses about the experience of cancer.

- ✓ I was working in a Nursing School so I was not part of the nursing team of the hospital. This information was thought to contribute to participants sharing their experiences without feeling intimidated.
- ✓ Their answers could contribute to improving nursing care because professionals would have information available about their needs and concerns during a relapse of the illness.
- ✓ Questions were also asked to more people who were in their same situation.
- ✓ All data was confidential and would not be discussed outside the interview itself except for its presentation as part of reports from the study where the patients would be wholly anonymous. Besides, only my co-researchers and I would read the data.
- ✓ The interviews would be recorded if they gave consent, and their responses would remain completely anonymous. Moreover, written consent was required from all participants.

This approach was thought to reduce the difficulties associated with communicating with outsiders. Furthermore, I made clear before the interviews that the information reported would not be disclosed to any family member (as is indicated next in the section on ethics). When various interviews were conducted, discussion came up about the appropriateness of informing participants that I was myself a relative of a patient with recurrent cancer. If participants knew about my professional and personal background, it was anticipated that they would feel more comfortable when disclosing their experiences to me. Therefore, it was decided to inform subsequent patients and family members about this fact. Interestingly, revealing this information was significant in helping me to build a good relationship with participants in the ongoing contact stage.

All the patients interviewed were asked to name one or two family members who were involved in their care and who accompanied them during inpatient or outpatient

hospitalisation. The patients identified the family member who was with them at the time of the interview.

Before commencing the interview, I took the time to repeat the reason for the interview, including the aim of the research and what would happen to the data. I also thanked the participants for taking part in the study. This helped me to develop an empathic and non-threatening atmosphere where the participants could feel comfortable with my presence. After these necessary steps, I asked the patients to recall the time when they were told that they had cancer and to report their experiences. This would help me to identify whether the patients knew their cancer trajectory and how much information they knew about their diagnosis, treatment and prognosis. Family members were asked the same question to open the discussion. During the interviews with patients and relatives, I asked them about the impact of a relapse of the illness and their perceptions of nursing care during the time of cancer treatment in the hospital. Although I had an interview plan, the participants' descriptions of their experiences guided the interview. I concentrated on what the participants were saying and I sought not to be directive by spending more time on active listening and less time talking. Through the interviews, I improved this interviewing ability.

As interviews went on, new questions were formulated according to the emerging categories obtained from data. The answers to the questions were followed up with open-ended questions to seek clarification. The questions were asked taking into account the flow of the conversation. To close the interview, I asked the interviewees if they had any questions and I thanked them again for contributing with their experiences.

Initially, I planned to interview patients within 24 hours of their agreement to take part of the study. This was thought possible, as I had intended to interview people during hospitalisation. However, as I decided to include outpatients, it did not become feasible to interview them at the hospital within 24 hours of their agreement to participate. The interview procedure was subsequently changed after ethical reflection. Rather than postponing interviews, they were conducted when a mutually

convenient time was arranged between the participants and me. Once the interviews with the patients were conducted, I asked the patients permission to interview their family member(s).

An aspect requiring attention referred to the researcher's background. It has been argued that participants' perceptions of the interviewer influence the interview interaction (Richards & Emslie 2000). When I introduced myself to the participants, I made clear that I was a qualified nurse not practising currently because I was involved in research. Hence, if participants required medical or nursing advice, I would take care to explain that they would be referred to their own GP/nurse as appropriate. For the most part, the families seemed comfortable with being interviewed, responding to my questions, and indicating when they did not understand the questions. Although it was the first time that I had spoken to the patients and their family members, I felt comfortable and established good communication with them. Overall, the participants appeared pleased during the interview. Some of them thanked me for listening to them.

On average, the interviews with patients took about 50 minutes. Most of the interviews with family members lasted about 30 to 40 minutes.

INTERVIEWS WITH NURSES

Following the interviews with the families, I approached and asked nurses for participation in the study. Early in the sampling procedure, the patients and their family members identified nurses from the University Clinic. I asked the families to name the nurse who had cared most often for them during hospitalisation and/or treatment. I next approached the identified nurse and asked her to participate in the study. This is defined as purposive sampling (Coyne 1997). After various interviews with nurses, purposive sampling was modified to theoretical sampling, as indicated by the grounded theorists (Glaser & Strauss 1967). This meant that the choice of the next interviews with nurses was determined by the emerging analysis of the data.

Therefore, I stopped asking the patients and family members to identify a nurse. Rather, I approached the nurses who I considered could give further information on the emerging codes and categories. This procedure was intended to provide me with plentiful information for the development of the theory grounded in the data (Glaser & Strauss 1967).

An important aspect related to the time of the interviews with nurses. Because I realised that time was limited in hospital, I gave the nurses the choice to conduct interviews at any time they suggested convenient for them. All the interviews were performed during the nurses' work shifts. Usually they were conducted during their lunchtime or at the end of the nurses' shift. All nurses (9 from the University Clinic and 5 from the Hospital) gave their consent to be interviewed.

According to Arbon (2004), nursing experience is more than clinical experience. It is a combination of progressive understanding in a specific field together with an understanding of the self and of others that seems to be individual in addition to transferable across fields in practice. This is because experienced nurses bring to practice understanding of other patients and other situations. Becoming experienced is related to accumulation of experience and acquisition of understanding over a period of time. In this definition it is important to differentiate between *being experienced*, which is associated to an existential event, and *being expert*, which is related to a specific context or field (Arbon 2004). In line with this author, I identified an experienced nurse as a qualified professional who had worked for at least 6 years in nursing and who was able to develop a therapeutic relationship and meet the needs of cancer patients and their family members.

In order to identify experienced and inexperienced nurses, I asked the nurses about the length of time they had worked in nursing and length of time they had practiced as cancer nurses. I found it important to classify nurses depending on the length of their career in an attempt to identify different responses regarding the focus of care. For example, I observed that inexperienced nurses often reported the need to provide psychosocial care in recurrence, although they did not always know how to do it in practice (as I shall describe in the analysis chapters).

USE OF INTERVIEW GUIDES

According to Streubert and Carpenter (1995), the researcher should expect the interview questions to develop and change. Three different interview guides were used in this study: one for patients, one for relatives, and one for nurses. Key issues arising both from the literature and from my nursing practice informed the design of the initial interview guides. Some main questions were listed in the guides to highlight the areas of interest in the study and to ensure that similar types of data were collected from the participants. A first question guide was developed and used during initial interviews with each of the groups of participants (Appendix 2). The questions in these interview guides were broad and provided direction for the study by presenting an initial description of the phenomenon of interest. After two sets of interviews with each of the groups, I modified them according to the analysis of the data. As data was being collected and compared, the interview guides evolved into an exploration of how participants came to understand cancer recurrence. When participants reported their experience in the same way as other interviewees, I identified an agreement in the categories. When I identified disagreement, I asked questions that sought explanations for the difference. For instance, I might ask something like this: “many nurses have mentioned that they found it difficult to provide emotional care although they identified it as essential in nursing cancer care. To what extent is this your experience?” These new questions helped me to find evidence that developed the emerging theory.

During data collection which lasted 21 months, the guides were modified four times to direct them toward specifying those points that were not sufficiently explored in the previous interviews. Some questions were modified, eliminated, or added as categories were emerging (Appendix 2). This approach seemed to contribute to the credibility of the study, as the collected data was guiding the inquiry process (Strauss & Corbin 1998).

PLACE OF THE INTERVIEWS

In the two selected centres, the interviews with families were conducted in the hospital context. Practical and economic considerations encouraged me to interview families in the hospital environment. This was because the centres housed patients coming from different parts of the region, and even different regions of Spain. However, if the families were living around the town where the hospitals were located, I offered them the option of being interviewed at their home. Despite giving some families this option, all the families preferred to have the meetings in the hospital.

In the University Clinic, interviews with patients were conducted in their room. This was possible because the rooms were individual, allowing patients to speak openly. Interviews with relatives were conducted in the nurse-manager's office of the unit that lent itself to speaking without interruption. In the Hospital, interviews with patients and relatives were conducted in a comfortable office that was generally used by the psychologist of the unit.

The interviews with nurses from both hospitals were conducted at the hospital in the nurse-manager's office of each of the units.

MEMOS

Memoing started in the beginning of the research and continued in parallel with data collection and analysis and writing-up. A memo can be defined as a piece of paper that informs about one or various aspects of the research. In effect, a memo was a note to myself about issues that came out during the research, ideas and hypothesis I had about the emerging categories, and relationships between categories among others. For example, I carried a note pad in my bag most of the time for writing memos. After each interview session, I went to my office to note any thoughts from the interviews with participants. I also wrote memos on the observations and the overall impressions of the interviews. I used memos in the form of word text,

schemas, and diagrams to write whatever concerns emerged during the process of the research. Besides, information about the structure of the families was registered using genograms in an attempt to provide a way of mapping family patterns and relationships as well as a better understanding of the patients' medical history (Appendix 3). These memos were useful later for the analysis because they threw additional light on the textual content and they facilitated the placing of the transcribed data into context. Accordingly, memoing captured the different aspects of the theory that emerged from the data.

Writing memos was central to developing the emerging theory grounded in the data, as argued by social theorists (Charmaz 2006, Wolff 2004). During the research process, I used four types of memos that I identified as methodology memos, theoretical memos, analytical memos, and descriptive memos. Methodology memos included notes about the characteristics of the sample, process of sampling, and issues related to data collection and data analysis. Theoretical memos compiled information about the codes, subcategories, and categories, which emerged from the data and their interconnection. Using diagrams and schemas in this type of memo was useful for understanding and interpreting the data from a specific case level to an abstract level of analysis. Analytical memos included notes about the reflexive thinking I conducted through the research, the decisions I made, and the changes that occurred during the research. Besides, I wrote aspects related to theoretical saturation and rigour of the study. Finally, descriptive memos included descriptive observations and reactions during the research process. Figure 5 illustrates below the different types of memos used in this research.

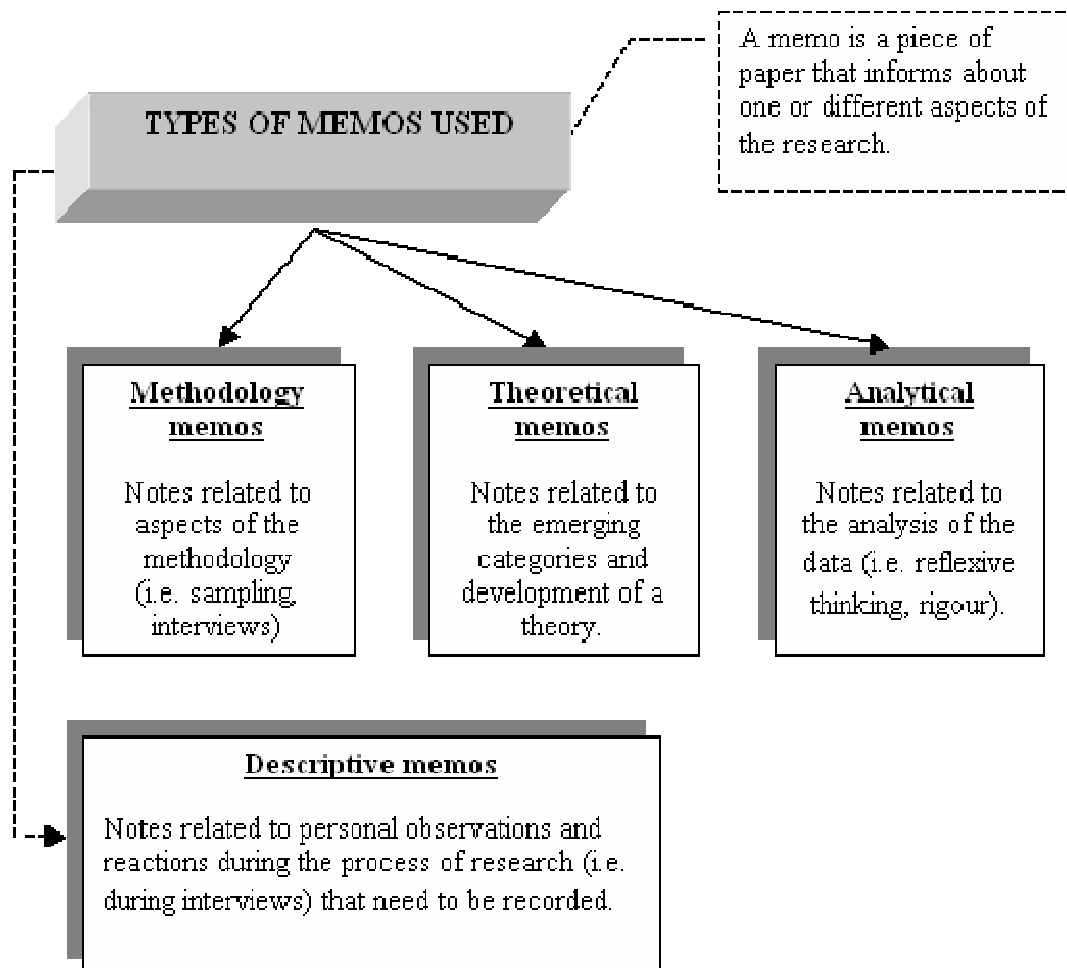


Fig 5. Types of memos used in the analysis

LITERATURE

Following the principles of grounded theory, literature was used as a data source (Glaser & Strauss 1967). Using literature contributed to increased validity of the qualitative research as I looked for patterns of convergence and divergence to produce evidence from the emerging categories in corroboration of the existing research (Chiovitti 2003, Lomborg & Kirkevold 2003).

As described in chapter 2, I initially reviewed literature to identify the kinds of research previously carried out in the area of cancer recurrence. This search assisted in focusing the research and prevented leading participants in the direction of what had been previously discovered (Chenitz & Swanson 1986). In line with methodological issues in grounded theory, I avoided conducting an extensive review prior to commencing data collection and analysis (Cutcliffe 2000, Strauss & Corbin 1998).

As the research progressed, I reviewed the literature as an ongoing process during data collection and analysis. My aim as I read was to compare literature with the emerging categories in the same way as I compared data with the emerging categories. This process was useful in clarifying and comparing categories with those in the literature as a data source. For example, documentation on psychological suffering, demoralisation, hope, and supportive care was searched to provide wider information on the emerging categories. A key issue during the analysis was that I found disagreement between some emerging categories like demoralisation and the literature. I tried to treat disagreement adequately and make sense of both the data from this study and the data from the literature. Additionally, I contacted an expert who had written about demoralisation and I asked him if he could recommend relevant references. I met an expert psychiatrist to talk about the difference between depression and demoralisation. The combination of methods helped me in the critical analysis and identification of the emerging categories in this grounded theory study.

Towards the completion of the data analysis, I undertook a comprehensive review of the literature relating to the physical and emotional impact of cancer recurrence. Furthermore, I performed literature searches to compare existing theories with the theory that I was developing (and that I will present in chapter 7) to ensure that the understanding that I presented was new and original.

THE ROLE OF THE QUALITATIVE RESEARCHER IN DATA COLLECTION

Qualitative research raises questions about how much to present and maintain researcher roles. Researchers need to decide how much to participate and how intensively they will become involved in participants' lives. Traditionally, in quantitative methodologies researchers are seen as outsiders and thus capable of being objective, a prerequisite to being scientific. In qualitative methodologies, researchers are usually considered as insiders who belong to the same social reality as people they are studying (Creswell 1998, Roberts & Snowball 1999). This perspective has long been an object of debate by researchers in the quantitative tradition, arguing that being part of the research process was not scientific (Shadish 1995). Qualitative researchers, in addition to arguing on the importance of qualitative methodologies in researching public health, advocate that the researcher is an important instrument in qualitative investigation (Baum 1995, Polit & Beck 2004). The justification for this is that qualitative researchers construct reality from individual experiences based on social interaction (Cutcliffe 2000). As a qualitative methodology, grounded theory enables the theorist to share interaction with participants and to take part in the grounded theory process. Yet, it is important that the grounded theorist ensures rigour in the inductive process and avoids invention of concepts and categories that are not grounded from the data (Cutcliffe 2000).

The degree of involvement in care provision was made clear from the outset when I informed all participants about my role as a researcher and not as a nurse. However, since research in nursing is still new in the Spanish healthcare context, the participants might have found it odd that I interviewed them. Indeed, some patients and family members thought I was a practitioner. From the outset, I made it clear that I was concerned in conducting this research because of personal and professional interests, as indicated earlier in this chapter. As a researcher, I had to find a new self since I had never adopted the role of researcher before. I found certain situations troubling, such as when a family member confessed to me that she was psychologically ill-treated by her husband, or when a woman expressed her wish to die to stop making her family suffer. These two situations were challenging for me,

not only on a professional basis but also on a personal and a moral bases. I wondered: “*Should I stop the interview? Should I offer her the support of other professionals? Should I act as a nurse and try to comfort her?*” A reflection on the persona I was adopting as a researcher and my persona as a human being brought me answers to these situations. Although the origin of suffering was different, I considered empathy and active listening as the most appropriate behaviour in both situations.

An important decision I had to make was whether to inform the families that I was myself a family member of a patient with a recurrence of cancer (as mentioned before in this chapter). Certainly, this information would influence the responses of the participants to some extent. Some authors have noted that the researchers’ perspective and interests inevitably influence aspects of the research process (Chew-Graham *et al.* 2002). However, after reflection and discussion with my supervisors on this point, I decided to give this information to the families in an attempt to create “communication between equals” where both the interviewees and the interviewer shared a common experience of facing recurrence. This information was thought to make discussion about emotional aspects of cancer easier. However, I was very aware during the data collection and the data analysis that I was acting as a researcher, so I could not allow my own feelings and opinions on the matter to govern the conversation with the interviewees and the interpretation of the data.

A final question in reflecting on the role of the qualitative researcher refers to the emotional nature of research (Gilbert 2001). Within the qualitative paradigm, the researcher has been acknowledged as an instrument in the research process (Rew *et al.* 1993). As a human-as-instrument, the researcher has emotions resulting from experiencing the world in a similar way as the participant. Far from being detrimental, emotion is considered essential in investigating sensitive topics (Frank 2005). According to Gilbert (2001):

It is not the avoidance of emotions that necessarily provides for high quality research. Rather, it is an awareness and intelligent use of our emotions that benefits the research process (p. 11).

In this study, both the families and myself had experienced common emotions after a diagnosis of recurrent cancer. Like the interviewed families, I myself had often been through similar fears and anxieties as a daughter of a survivor who had faced two recurrences of cancer. Indeed, there were times during interviews when I felt family members' experiences as if they were my own. Interviewing these families was challenging, but at the same time, it gave me a sense of belonging and it helped me to see the common experiences of family members who accompanied their relatives through the cancer trajectory.

Interpreting data

ANALYSIS IN GROUNDED THEORY

In grounded theory, data collection and analysis are performed simultaneously (Strauss & Corbin 1998). This strategy, which was used to analyse data in the current study, contributed to seeing where the gaps existed and which categories needed further exploration. Data analysis was based on the constant comparative method, that was comparing different participants' experiences and views, comparing responses from the same individual at different points in the interview, comparing data with emerging categories, comparing emerging categories with new categories, and finally comparing interconnectivity between categories (Charmaz 2003). This analytical method entails following a process of coding that occurs at three levels: open coding, axial coding, and selective coding (Glaser & Strauss 1967). Using the three-step analytical procedure helps the grounded theorist to break down the data, conceptualise, and put the data back together in new ways with the aim of developing an emerging theory grounded in the data (Priest *et al.* 2002).

Open coding involves dividing data into concepts that represent important aspects of the phenomenon under study, and grouping and labelling the emergent concepts into categories (Glaser & Strauss 1967). The process consists of going through the texts line-by-line and sentence-by-sentence searching for salient words and concepts.

Adapting from the work of Strauss and Corbin (1990), Gibbs (2002, p.170) recommends a variety of other techniques to conduct open coding, as presented next. *Far out comparisons* consists of thinking of opposed examples that share similar characteristics with the idea or phenomenon being examined. The aim behind this strategy is to compare the different meanings of a specific word or sentence with other situations, seeking to elucidate all possible meanings of a condition. An example of how I used this technique is commented later in this section. Another practice is the use of specific phrases like “never”, “always”, “again”, documented as *waving the red flag* (Gibbs 2002). These words are commonly used to emphasise frequency and extent of a phenomenon, though they are not often used consciously but as part of a sentence. Therefore, they have to be examined closely, as I did in this study.

Axial coding is the procedure by which data are put back together in new ways by making connections between categories (Glaser & Strauss 1967). At this step, it is important to constantly compare new data with emerging codes and construct initial relations between categories.

Selective coding is used to select the core category or central category, systematically relating it to other categories, and filling in categories that need further refinement and exploration (Strauss & Corbin 1990). In this phase of the analysis, categories should be reduced by interconnecting redundant categories that have similar meaning and by retaining the most representative categories. The most salient categories will explain what basic social processes are emerging from the data (Glaser & Strauss 1967). Effort should be made to integrate the categories and their properties and to determine the main category that links with the other categories to present a theory that describes the phenomenon under study. The aim of this coding is to look at patterns in the data across sources and in relation to the sequence of events and to validate relationships between categories with the aim of interpreting data at an abstract level and build up a theory that informs about the nature of the phenomenon being researched (Creswell 1998).

DEVELOPMENT OF THE ANALYSIS IN THIS STUDY

EARLY STAGE OF THE ANALYSIS

As Tesh (1990) suggested for researchers who look for relationships between and among identified categories grounded from data, I sought “connections” to seek “explanations”. I tried to find out more than just *what was*; I also tried to find out *why* it was (Tesh 1990, p. 85). This would permit me to understand why individuals behave in a specific way when facing cancer recurrence.

After each instance of data collection, I compared data to data and interview to interview. I listened to each tape and I transcribed interviews entirely. In order to familiarise myself with the data, I read through each interview and I numbered paragraphs of the transcripts according to the question number of the interview guides. Then, I carried out a deeper reading in order to identify areas of interest. I analysed paragraphs of each interview to understand what the data indicated. As I read the transcriptions, relevant words and sentences expressing aspects of an experience were underlined in pencil and keywords were written in the margin of the paper. To help me with this, I followed Strauss and Corbin’s (1998) suggestion about inquiring the data through the analytic process. I asked myself questions such as what was going on, who was involved in the phenomenon of recurrence, how were individuals managing the situation, and why did individuals react in a certain way to seek deeper understanding of what the data were telling me. These questions helped me to identify information that was relevant to participants. Particular attention was paid to looking for psychosocial processes and to examine how the participants were managing cancer recurrence. The method of constant comparison was also used from the early stages of analysis, as recommended by grounded theorists.

Based on the interpretation of the data and comparative analysis, I assigned categories to areas of information. Making comparisons helped me interpret the meaning of a word, a phrase, or a sentence. Whereas sometimes it was easy to understand what data meant, other times it was not evident how it should be interpreted. When this happened, I read the “obscure” piece of data several times and

searched for synonyms of the words used by the participants. Another comparative technique that I often used was to look for opposite meanings. I tried to identify what the data did *not* say to better understand what was implied by a word or a sentence. Some of the interviewees responded in the same way to similar questions whereas other interviewees responded to the same question with differences. Therefore, I compared responses of the participants from different parts of the interview to identify if the data was the same for similar questions.

It is important to recall that interview transcripts were in Spanish. From the beginning of the research, I decided not to translate all the transcripts to English because of lack of time. The way I worked was as follows. First, I interpreted the data from the Spanish transcripts. Once I mentally identified the categories, these latter were translated into English. This was possible because, though I am not bilingual, I am a fluent English speaker (further information on rigour in translation is presented later in this chapter).

A label identified each category that emerged from the interpretation of the meaning of a word, part of a sentence, or an entire sentence. As suggested by Strauss & Corbin (1998), I sought to avoid labels that were merely a description of the text but made an effort to formulate conceptual terms that expressed what the data stated. Whenever possible, the participants' own words were used to name codes (Strauss & Corbin 1998). Labelling concepts used by the participants helped to ensure credibility of the findings, meaning that the data corresponded to the participants' own words. To explain the meaning of the emerging categories, I defined their properties, also known as attributes or characteristics pertaining to a category. As new data was compared with previous data and categories, I observed that there were categories that overlapped but they were identified with different names. Hence, I unified the categories and labelled them with the same name in order to ensure consistency.

In summary, initial comparison of data was analysed through open coding, meaning that the data was fragmented into codes and categories. The next step was to put data back together in new ways by making connections between the identified categories.

MIDDLE STAGE OF THE ANALYSIS

At the beginning, it was hard to make connections between the categories. However, as I made progress in the analysis, I more quickly identified relationships that I previously found it difficult to interpret. This process coincided with Strauss and Corbin's suggestion that "the researcher's theoretical explanations are fuller, more specific, and denser because properties and dimensions that previously might not have been visible to the researcher become evident once he or she is sensitive to them" (p. 96-97). Being in contact with the data allowed me to become more familiar with the information, thereby helping me to understand better what the participants said. In addition to storing data in two different formats (Microsoft Word and Nudist), I also kept a print copy of each transcript so that I could refer back to any passages. Having access to original data was important to ensure that the data was being analysed in context and thus the theory was grounded in the data (Charmaz 2006).

In order to find relationships between and within categories, I asked myself the following questions: "Are patients' experiences the same or different? Are relatives' experiences the same or different? Are nurses' experiences the same or different? In what sense are experiences similar or different? How do the categories interrelate?" These questions were useful to create different levels of abstraction. As I compared new data with previous data, different levels of codes were emerging (concepts, subcategories, and categories). As mentioned earlier, the process of constant comparison was used through the entire analysis as well as continuous questioning of the data.

It is the strength of grounded theory that conceptualisations are grounded in the empirical world (Pandit 1996). At the beginning of the data collection, I designed the interview guide to ask the participants questions about what it meant to them to deal with a recurrent cancer. Initially, I had planned to focus on the recurrent phase, though I would let participants talk about what they considered important, including first diagnosis of cancer. However, as interviews went on, I observed that first diagnosis of cancer was important in the current experience of recurrence. All the

participants referred to their first experience with cancer, including nurses who talked about the differences existing between patients with a primary tumour and patients with recurrent cancer. Hence, I realised that the issue of time and past experience with cancer was paramount in the participants' descriptions. Therefore, although I had entered the research with the phase of cancer recurrence as the centre of attention, I found it significant for the study to incorporate questions about previous experiences with cancer. The following interviews with patients and family members included question such as "Is there any difference (in managing the illness) between the first diagnosis of cancer and the current situation?" As the interviews continued, I could "see" how important the concept of time was in the experience of recurrence. More questions that implicitly enquired about time were added in the interview guide of patients and family members. For instance, I introduced questions like "How do you use your previous experiences with cancer to cope with the current relapse of the illness?" In the same way, I included questions inquiring about the issue of time in the nurse interview guide. Questions, for example, were: "Is there any difference in the way you care for newly diagnosed cancer patients and patients with recurrent cancer?" In line with grounded theory methodology, it can be said that I conducted a typical grounded theory analysis. The analysis involved frequent revisiting of the data in the light of the new analytical ideas that emerged as the data collection and analysis progressed.

At this stage of the analysis, I compared the emergent categories with existing literature. As explained before, I carried out an ongoing review to identify existing evidence that could inform me about the emerging categories related to suffering, impact of recurrence on the family and nursing support among others. The aspect of time emerged early in the interviews. Significant thoughts about time and temporality were followed up in subsequent interviews and I performed a simultaneous literature search on the philosophical concepts of time and temporality.

EMERGENCE OF CATEGORIES AT HIGHER LEVELS OF ABSTRACTION

In this stage of the analysis, I still had difficulties in recognising the common experiences of the participants regarding cancer recurrence. It was apparent that of the three groups, patients and family members perceived similar realities about the nature of the experience of recurrence and its impact, whereas nurses perceived another reality. It was not until after much reflection and refinement of categories that I identified the common understanding of the phenomenon of recurrence of the three groups. At this stage, I started seeing the categories at a higher level of abstraction, enabling me to integrate categories into an organised description that explained the social phenomenon of recurrence. This creative process has been named theoretical sensitivity. This is described as the ability “to see the research situation and its associated data in new ways and to explore the data’s potential for developing theory” (Strauss & Corbin 1990, p. 44).

The process of how I conducted the analysis in this step of the research is given next. I looked for concepts that were in essence very similar, and could eventually be labelled with the same name. The development of main categories was slow, beginning with the identification of potential categories, which progressively became firmer and firmer. I made constant comparisons to see whether connections existed between categories. As open and axial coding proceeded, patterns in the data started to emerge and tentative hypotheses or statements of relations between phenomena were generated. Once each category was properly characterised, I found out how frequently a perspective was described and how much it was shared among patients, family members, and nurses.

However, there were still a substantial number of unrelated categories. Organizing them to find a core concept that brought all the data together into a coherent theory was the hardest work. This was because the intellectual work was focused on verifying if these statements were true compared with the rest of the collected data or if I needed to collect more data. After a considerable time of looking for one central phenomenon, I did not discard the possibility of identifying more than one core categories, although Strauss and Corbin (1990) advise selecting just one. After a

period of intellectual turmoil, I realised the importance of being patient and letting the analysis process develop gradually. I called this period “a lesson of intellectual maturity” because it was a time of frustration and uncertainty and I needed to learn how to cope with it. Time and reflection were central for developing analytical skills and ensuring rigour of analysis.

In the inductive process of building a theory, data are interpreted not in isolation, but in light of their relationships (Strauss & Corbin 1998). The relationships between the emergent categories in this study helped to bring together data from the different sources in an attempt to identify patterns that explained the experience of cancer recurrence. Nudist, a computer software package for qualitative analysis, was useful in performing this task, as will be described later. In addition, writing-up has been described as a way of interpreting qualitative material (Richardson 1998). This was a strategy I used from the beginning of data collection, guided by Glaser’s recommendation that memos are the theorising write-up of ideas about substantive categories and their relationships as they develop during data collection and analysis (Glaser 1998). As mentioned before, writing up memos helped me to analyse issues that emerged from the data. After all the data had been collected, I sorted out the written memos and compiled the pieces of writing I had made during the research process to present the findings of this research and theory generation. See Figure 6 for the analytical process used in this study.

ADDRESSING NON-VERBAL COMMUNICATION IN THE ANALYSIS

The experience of living with cancer recurrence was explained through the participants’ words and their body language. In the analysis of the data, I paid attention to both verbal and non-verbal communication. It is well known that communication is not only verbal but it also includes non-verbal language. Usually when an emotive topic was discussed during interviews, body language and looks said as much as words. Many of my personal observations to the interviews with the patients and relatives included notes about how they expressed their emotions

through their gestures and facial expressions. I thought it was relevant to make notes of it because the transcripts did not capture it. The patients' and relatives' body language and auditory cues revealed meanings of words, such as the nature of suffering. Through the body, the participants sometimes communicated more of their experiences than they did when using words. Facial expression such as apathy, eye expressions such as a sad look, and body movements like rocking their heads were indicative of the participants' suffering. Other signs of distress were shown through a quiet tone of voice and silent pauses. The analysis of the silences during the interviews and my field notes about non-verbal communication complemented the evidence about the impact of recurrence within the families, though they did not always articulate it with words. As part of the findings, I give information about non-verbal communication so that readers may better understand the world of the participants.

CIRCULAR PROCESS AND VALIDATION OF CATEGORIES

Discovery of the categories was more circular than linear. The emergence of the categories was constantly checked by making comparisons. Three different stages were passed through to ensure validity of the emerging categories. First, in the initial stage of the data analysis, while I was gaining knowledge about how to use Nudist, I wrote new categories on the left-hand side of the transcript pages and I highlighted segments of a sentence, words, or paragraphs using fluorescent pens. Three interviews were coded following this process. Once I learned how to use Nudist, I re-analysed the same three interviews and entered the identified categories using the software. Although analysing three of the interviews twice may seem a waste of time, I found it useful. This approach helped me to check the validity of the emerging categories, as I compared whether categories that were identified in the first round were similar to those described in the second round. Surprisingly, similar categories were identified on both analyses but with some linguistic differences.

Although categories were identified in this initial stage, I still felt the need to return to the previous coded interviews in Nudist and to analyse them a third time. This could be reasonable if it is considered that I was a novice researcher in grounded theory, and as indicated by some authors (Backman & Kyngäs 1999), I could encounter challenges in using this qualitative methodology. This step, although time and mentally consuming, helped me to be in permanent contact with initial data and to feel confident with what I was doing. Going back to the interviews allowed me to see important findings emerging from the initial analysis. This is described as “doubling-back steps” where current data collection and analysis are checked against previous data collection and analysis (Glaser 1978, p. 16). Through the process of analysis, I used this technique to ensure rigour of analysis.

In addition, an external researcher checked the validity of the initial emerging categories. As mentioned earlier, the procedure of using different researchers to interpret the same body of data is defined by Denzin (1978) as researcher triangulation. The researcher was a Spanish nurse who was a fluent English speaker and was familiar with qualitative analysis. Independently, the nurse coded a set of three interviews and her analysis was compared with mine. Where there was disagreement between my codes and that of the nurse, further discussion was conducted until we resolved discrepancies. This approach would contribute to reduce bias and to provide appropriate validation of the initial analysis. The discussion with the external researcher and comparison of her analysis with my interpretation of the data helped me to validate the categories I had identified until that time. The discussion also helped me to pay attention to words that might appear insignificant but they had important meaning in subsequent data collection and analysis.

In the central stage of the analysis, I saw the need to check the validity of the emerging categories again. This was because at this stage, new categories were identified as well as core categories. I had to ensure that what I understood from the data was what the data was telling me and not what I thought the data was saying. Three interviews, which were different from those given to the first external researcher at the early stage of the analysis, were given to a third researcher for

analysis. This time the researcher was an expert in quantitative research and diabetic care but had some experience in analysing qualitative data. I believed that comparing the perspectives of both an “insider researcher” (myself) and an “outsider researcher” (the third researcher) could increase the validity of the emerging categories. This was because the outsider might be more inclined to identify aspects of the experiences of the participants that I (the insider) might avoid because the information was obvious for me. I defined an insider as a researcher who belonged to the same nursing area as the topic of the research under study. In contrast, I defined an outsider as a researcher who belonged to a different nursing area from that of the topic of the research being studied. The meeting developed in the same way that with the first researcher. Having the interpretation of the two external researchers was seen as important in validating objectivity of emergent categories and ensuring rigour of the analysis and the theory generation. Besides, the process of cyclical analysis through the research was important in the inductive process of building the theory (refer to Figure 6).

FROM THEORETICAL CODING TO THEORETICAL SATURATION

Constant comparison of data to data, data to codes, and codes to categories informed me about the focus of the developing categories and the gaps in the data. In an attempt to fill these gaps, I developed new questions based on the earlier findings and went back into the field to selectively gather data through theoretical sampling that would probably give information about the emerging categories. In addition, I reviewed the memos that I had written and I went back to the previous interviews to look for data that might have been overlooked. Theoretical coding, which is described as an ability to select data that can bring new light to the development of the emerging theory, continued into the final writing phase. Conducting this analytical work allowed me that the level of abstraction of the categories increased progressively.

Furthermore, attention was paid to detecting points in the data, such as an event, a person, or an experience that were different from the rest of the data. This analytical

procedure has been referred to as outlying cases (Strauss & Corbin 1998), also named negative cases or deviant cases (Mahoney & Goertz 2003). Discovering these outliers increases variations of the theory because they present alternative descriptions of the data, at the same time as it increases density to the theory. Strauss and Corbin (1998) explained that variation of the categories is reached by “being able to show that even within a category, there are differences in how one experiences a rite of passage” (p. 158). By density, they meant that “all (within reason) the salient properties and dimensions of a category have been identified, thereby building in variation, giving a category precision, and increasing the explanatory power of the theory” (Strauss & Corbin 1998, p. 158). In essence, the use of outlying cases enhances generalisability of the theory (Strauss & Corbin 1998).

As a strategy to fill gaps and add variation and density to the theory, I examined negative cases that supported alternative explanations of cancer recurrence from the participants. For example, the initial phase of data collection revealed that the experiences of patients and family members were relatively similar concerning the emotional impact of living with recurrent cancer. Most of the interviewees described their experience as negative and emotionally painful. However, in the course of an interview with a woman receiving treatment for a second recurrent cancer, relevant data, conflicting with the previously collected data, emerged from the conversation. The woman reported positive aspects of living with recurrent cancer. From the analysis of that interview, it appeared that recurrence acted as catalyst that promoted development. Then, recurrence was perceived as a call to new action. The challenge it provoked seemed to bring the patient new coping mechanisms that served to strengthen her adaptation to the illness. Such an interesting finding necessitated further exploration in later interviews. Hence, I introduced a new question to the guides of patients for follow-up interviews. This question related to the significance recurrence had for the patients, and what the disease had brought to them, if anything. In the next interviews, some patients and family members expressed the positive aspect of having the disease, contributing to the development of a subcategory untitled “*suffering, growth, and cancer*” (developed later in chapter 6).

The collection and analysis of the data continued until theoretical saturation was reached, as advised by grounded theory. This happened when no new categories emerged despite collection of new data. In this study, theoretical saturation was reached after conducting 41 interviews and having a variety of data regarding the social phenomenon of cancer recurrence.

COMPUTER ASSISTED ANALYSIS

Interview transcriptions and memos were analysed with the aid of NUD*IST (Nonnumerical Unstructured data: Indexing, Searching, and Theorizing). This computer software package assists in the storage, organisation and search of data as well as enabling the structure of a wide quantity of data, such as combinations of different sources of data (Creswell 1998). There are other software packages designed to handle qualitative data, such as AQUAD, the Ethnograph, and ATLAS/ti (Rodriguez 1997). However, it has been suggested that NUD*IST is particularly useful to grounded theorists because it gives good support for theory development (Charmaz 2003, Gibbs 2002). Though using a computer package is said to help organising and retrieving complex data with the potential to improve the rigour of analysis, it also bring some limitations (Weitzman 1999). For example, using computer software requires that researchers first learn about the program, and the initial steps of the analysis are time-consuming and mentally challenging (Weitzman 1999). Moreover, no package can take the place of methodological training (Pope *et al.* 2000). That is, software does not do qualitative analysis. It can find text with codes that the researcher has applied and it can reorganise data. However, there is no software capable of interpreting judgements or determining relationship among categories.

The details of how I used the software are given next. I started coding pieces of meaningful words using what in Nudist is called “free code”. This type of preliminary coding, called open coding in grounded theory, grouped ideas of how respondents conceptualised cancer recurrence and its impact on their lives. After

various interviews, I realised that I had a large amount of codes and that I needed to reduce them in order to keep ideas clear and tidy. I thus started to develop “tree codes”, which are codes that have subcategories that allowed me to organise ideas in groups or broader categories. In the process of organising the data, I started to develop an understanding of the participants’ view of the world. To categorise participants into three groups, I gave different colours to each group of participants; red for patients, green for family members and yellow for nurses. This technique helped me to rapidly visualise the participants’ group in the Nudist window as well as informing me about those documents that had been coded.

Grouping the data together into meaningful categories and subcategories allowed me to gain an initial overview of the way the conceptual framework was developing. The generation of categories was constantly recycling through the stages of analysis until the theory was developed.

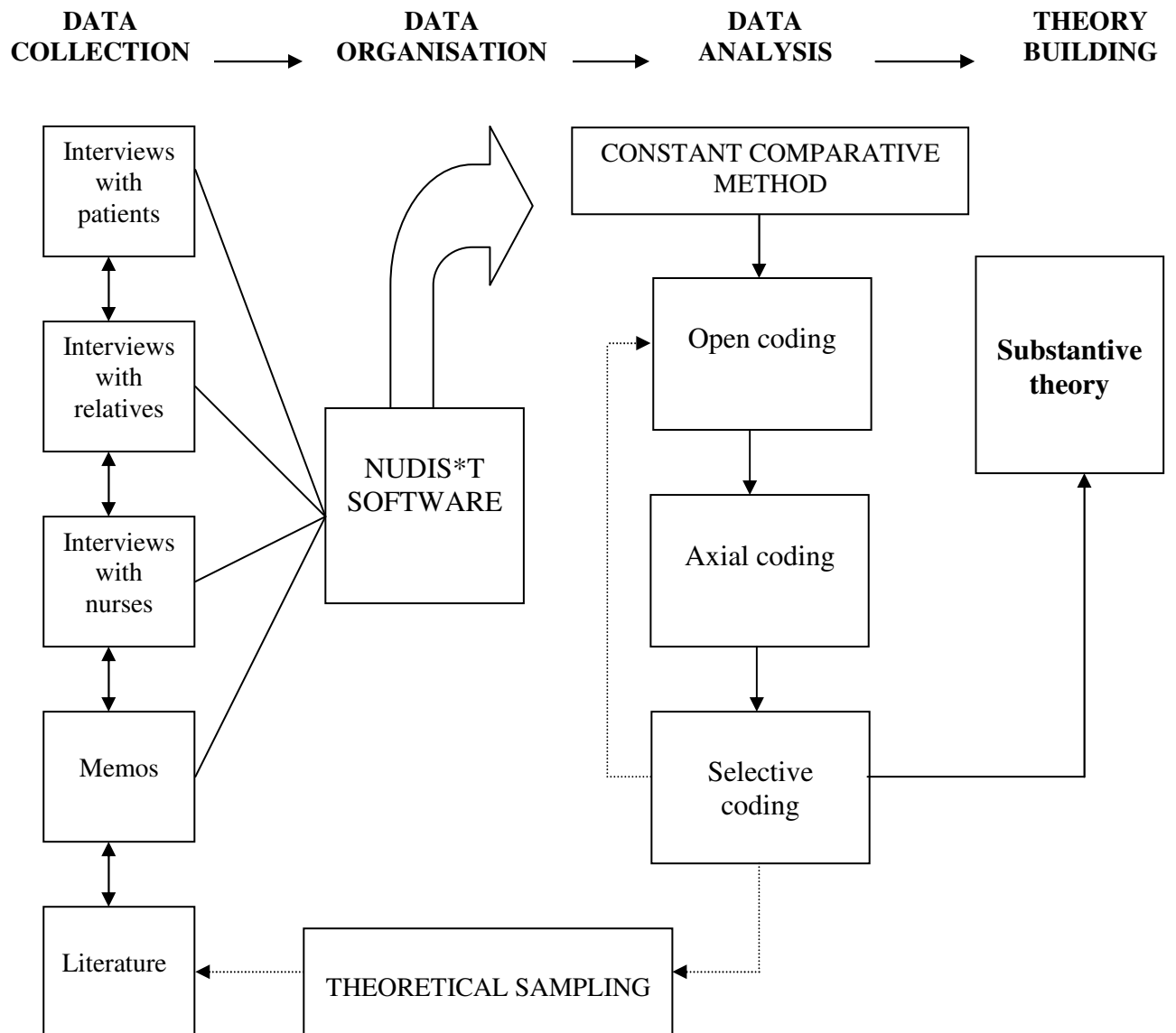


Fig. 6 Analytic research process used in this study

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE PARTICIPANTS

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE FAMILIES AND PATIENTS' MEDICAL RECORDS

A heterogeneous sample of cancer patients with a recurrence was enrolled in a cross-sectional study. At study entry, socio-demographic and medical information related to age, gender, marital status, cancer site, cancer stage, and type of cancer treatment was collected from patients (Appendix 5). A total of 15 patients were interviewed. Nine of them were female and six were male. The average age was 55 years, the oldest being 78 years old and the youngest 41 years old. The different types of primary cancer were breast, colon, lung, pancreas, rectum, and ovarian cancer. Nine of the patients were experiencing a first recurrence, five were being treated for a second recurrence, and one patient was experiencing a third recurrence. Regarding the time since first diagnosis of cancer, the average survival ranged from 5 to 10 years, the longest survival since primary tumour being 15 years and the shortest 9 months. All the patients except one who was hospitalised to manage chemotherapy effects were receiving antitumoral treatment for recurrent cancer (see Table 1).

TABLE 1	
Medical records of patients (n= 15)	
<i>Variable</i>	n
Sex	
Female	9
Male	6
Age	
40- 50 years	6
51- 60 years	4
61- 70 years	4
71- 80 years	1
Number of recurrence	
First	9
Second	5
Third	1
Extension of recurrence	
Local	5
Regional	2
Distant	8
Time since first diagnosis	
6- 11 months	1
1- 2 years	4
2- 3 years	2
3- 4 years	0
4- 5 years	0
5- 10 years	5
10- 15 years	3
> 15 years	0

The time since diagnosis of recurrent cancer ranged from a week to a year at the point of the interviews. The interval between primary cancer and first relapse ranged from 9 months to 13 years, meaning that some of the patients had experienced a long-term survival before recurrence (refer to Table 2 for details about survival of cancer patients).

TABLE 2 Information about cancer survival and time of recurrent cancer							
Gender	Age	First cancer	N° of recurrence	Time since first cancer	Interval between first cancer & first recurrence	Interval between 1 st & 2 nd recurrence	Interval between 2 nd & 3 rd recurrence
Woman	46	Breast	2	15 years	13 years	1 year	-
Woman	48	Breast	2	11 years	8 years	2 years & 4 months	-
Woman	45	Ovarian	1	1 year & 3 months	1 year	-	-
Male	62	Lung	2	8 years	6 years	1 year & 8 months	-
Woman	42	Breast	1	8 years	7 years & 11 months	-	-
Woman	41	Breast	2	7 years & 4 months	1 year & 4 months	5 years & 3 months	-
Male	59	Pancreas	1	2 years & 5 months	2 years & 4 months	-	-
Male	54	Lung	1	2 years	1 year & 9 months	-	-
Woman	52	Breast	3	7 years	4 years	1 year	8 months
Male	69	Lung	2	5 years	4 years	6 months	-
Woman	65	Pancreas	1	1 year	11 months	-	-
Male	78	Colon	1	13 years	12 years & 7 months	-	-
Male	62	Rectum	1	1 year & 2 months	1 year & 1 month	-	-
Woman	57	Colon	1	9 months	8 months	-	-
Woman	46	Colon	1	10 months	9 months	-	-

Regarding the settings where the patients stayed, 11 of them were receiving treatment in an Oncology Day Unit, 2 in an Oncology Week Unit, and 2 in a Medical Inpatient Unit. The majority of the patients interviewed were in the University Clinic (see Table 3).

TABLE 3	
Location of patients in the settings and centres	
Nursing setting	N° of patients (%)
Day unit	11 (73)
Week unit	2 (13)
Inpatient unit	2 (13)
Hospital	
University Clinic	10 (66)
Public Hospital	5 (33)

All the patients in the University Clinic came with at least one family member, usually their spouses. Patients were also accompanied by other family members: children, a brother, and a son-in-law (see Table 4 below about relationship of family members to patients).

TABLE 4	
Relationship of family members accompanying the patients	
Relationship	Number
Spouse	9
Daughter/son	3
Sibling	1
Other relative	1

Fifteen families participated in this study. All the patients but one were married and lived with their spouse. Of the fourteen married couples, thirteen had children and one couple was infertile due to the cancer treatment the woman received at an early age. The patient from each of the fifteen families was interviewed. In 10 families, the patient and one of his/her family member were interviewed. In 2 families, the patient and two of his/her family members were interviewed. In two families, only the patient was interviewed because the relative could not be contacted during ambulatory treatment. In one of the families, the wife who accompanied the patient initially agreed to participate but when I contacted her again to conduct the interview, she declined arguing she was highly distressed. The relationships in each of the families and other relevant information of their members are presented through genograms in Appendix 3.

The motivation of the patients and the family members who consented to participate was because, in most of the cases, they felt they could help others by telling their story. A few argued that the study sounded interesting. Four additional families were contacted but declined to participate either because of early contact after diagnosis of recurrence or because they were highly distressed and they were not prepared to recall their experiences.

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE NURSES

All of the interviewed nurses in this study were female and Caucasian. There was no option to interview male nurses because the nursing staff in the four-selected setting was female. Interviews with nurses included both experienced and inexperienced nurses, ranging from nurses working for 1 year to more than 15 years (see Table 5 for details about nurses' demographic and professional characteristics).

TABLE 5					
Nurses' demographic and professional characteristics					
Age	Years as qualified nurse	Cancer training	Years in cancer nursing	Setting	Centre
29	5	yes	5	ODU	A
27	6	yes	6	MIU	A
30	10	yes	10	OWU	A
24	4	yes	3	MIU	A
48	28	no	6	ODU	A
50	24	yes	24	ODU	A
36	14	yes	14	OWU	A
30	7	yes	7	ODU	A
35	7	yes	7	OWU	A
49	29	no	19	ODU	B
31	5	no	2	ODU	B
25	4	no	1/2	ODU	B
53	33	no	33	ODU	B
40	18	no	14	ODU	B
ODU= Oncology Day Unit; OWU: Oncology Week Unit; MIU= Medical Inpatient Unit; A= University Clinic; B= Public Hospital					

Ensuring rigour

METHODS USED FOR ENHANCING RIGOUR IN THIS STUDY

In quantitative research, a study is judged by how well it meets the standard of validity and reliability (Robson 2002). In qualitative research, however, it is a question of trustworthiness. Researchers have identified four measures of rigour to assess trustworthiness in qualitative research (Lincoln & Guba 1985). These are credibility, transferability, dependability, and confirmability. Others ways to help

enhancing the trustworthiness of qualitative analysis are to look for negative cases, to use triangulation (Patton 1990), to check the theoretical construction generated against other researchers, and to use participants' actual words in the theory (Chiovitti 2003). The procedures above were used to achieve methodological rigour in the present study. In addition, I used reflexivity throughout the research process, as it is said to present true and objective data (Finlay & Gough 2003, Gordon 1997, Koch & Harrington 1998).

CREDIBILITY

Credibility refers to the authenticity of the data, meaning that data should correspond to the perceptions of participants taking part in a research (Robson 2002). Credibility is reached when the study is accurately described and what is observed corresponds with what is reality. One way of ensuring credibility of qualitative data, particularly in phenomenology, is to give findings to participants to validate results (Creswell 1998, Hallett 1995). In this study, however, there were two reasons to omit inviting participants to validate the emerging theory. The first reason, and the most important, was because in grounded theory researchers are advised not to validate results by presenting them to the participants. This is because many participants:

“do not understand the summary benefit of concepts that go beyond description to a transcending bigger picture....GT [Grounded Theory] is not their voice: it is a generated abstraction from their doings and their meanings that are taken as data for the conceptual generation” (Glaser 2002, p. 5)

The second reason, was that I found it difficult, if not impossible, to approach interviewee families for validation of final reports. This was because most of them were not resident in the region where the research was conducted. Credibility was thus ensured using other techniques presented next.

First, to verify accuracy of results, online and face-to face supervision meetings were periodically held with my supervisors. Discussion about the direction of the research with trusted colleagues was of value to increase the credibility of the data. Besides, I participated in a three-year PhD European Programme where I had the opportunity to share the development and findings of the research with other European PhD students. Preliminary results were also presented in seminars. Anonymity and confidentiality of the data were guaranteed during the entire inquiry process. These procedures increased the opportunity to point out misinterpretations and provided information that I had not noted. In addition, written transcriptions of the interviews were used to support the meanings and interpretations presented in the findings as well as to keep data in context (Patton 1990).

TRANSFERABILITY

Transferability refers to the generalisation of the study, that is, the ability to apply findings to different situations (Robson 2002). Using a maximum variation sampling, which in this study consisted of obtaining data from different sources (patients, families, nurses) and different contexts (two hospitals and four units), contributed to an optimal level of transferability. The triangulation of distinct sources of data brought diversity of circumstances and could contribute to the possibility of extending the results of this research to other populations and contexts.

Selection of multiple sites is also suggested to give a more representative sample (Polit & Beck 2004). It could not be claimed, however, that all participants in this research would have the same perceptions and feelings of cancer recurrence. This was, firstly, because qualitative research is not concerned with issues of generalisation. Secondly, as emphasised through this thesis, each individual is unique. However, if the findings of this research were to be used in other places and conditions, then recruiting information from families and nurses from two different hospitals would allow a clearer understanding of the complexity of the phenomenon of cancer recurrence and might contribute to a higher quality of the study.

DEPENDABILITY

Dependability is concerned with the degree of consistency of a study, meaning that the stability of the data if the research is repeated (Robson 2002). To ensure the dependability of the collected data, reports of methodological decisions made during the inquiry process, referred to as audit trails (Lincoln & Guba 1985) were documented. Through the research, I described the process of selection of participants as well as any methodological changes that happened. Besides, the final report included a detailed description of the steps and results of the research and a full record of the decisions that were made in relation to the development of the study. This strategy would permit other researchers to replicate this study.

CONFIRMABILITY

Confirmability concerns the concept of objectivity of the data (Robson 2002). Others have suggested that confirmability occurs when the results are based on all data and not on a few select findings (Silverman 2000). To ensure neutrality of the data and thus reduce possible bias and distortion of the data, I used different strategies. First, writing memos was useful in establishing distance from the data, since awareness of my own feelings was taken into account. Second, comparing the data of the interviews with available sources, such as literature, enabled me to question if my interpretations of data really derived from empirical data or if perceptions derived from my personal background. Silverman (2000) suggested the use of the refutability principle, which related to questioning initial assumptions about the data, to achieve objectivity. The constant comparative method based on the principle of refutability (Glaser & Strauss 1967, Strauss & Corbin 1998) was therefore used in this study throughout the entire analysis process. In essence, I sought to refute my initial assumptions about cancer recurrence to achieve objectivity of the findings and to strengthen the developing theory by following the constant comparative method itself. Finally, as described earlier, two external researchers validated categories in the initial and middle stage of the analysis.

Although grounded theorists seek, as far as possible, to achieve objectivity of data, from the grounded theory approach the researcher is viewed as a social being who creates and recreates social processes (Baker *et al.* 1992). Further, Lincoln and Guba (1985) stated that the researcher's values and beliefs are part of the grounded theory process. In a similar view, Cutcliffe (2000) indicated that the researcher's experiences could be a source of data. Strauss and Corbin viewed the researcher's professional experience as a source of sensitivity in that the researcher can "move into an area more quickly because s/he does not have to spend time gaining familiarity with surroundings or events" (p. 47). Of importance, however, is that the researcher acknowledges his/her previous knowledge in order to indicate how the emergence of categories may be influenced (Cutcliffe 2000). In the context of this study, I recognised that my experience with cancer recurrence might bring concepts for the study. That is why since the planning phase of the research, I paid attention to my personal and professional backgrounds, particularly during interviews with families and analysis of the data. Throughout the research, I practiced a continued reflexivity that helped me to define my own perceptions and distanced me from the data.

REFLEXIVITY

Reflexivity is central to qualitative research in Health and Social Science (May 1998). Reflexivity allows researchers to become conscious of the interaction between them and the research, contributing to the trustworthiness of findings (Finlay & Gough 2003). While there is no doubt about the importance of being reflexive during interviewing and interpretation of data in terms of enhancing rigour in qualitative research (King 1998, Koch & Harrington 1998, Waterman 1998), there are concerns regarding its difficulty and practicality (Gordon 1997, Mauthner & Doucet 2003). For instance, few methods offer specific ways of doing it. May (1998) structured reflexivity into two dimensions: the endogenous and the referential. Endogenous reflexivity related to the examination of the processes by which communities constituted their social reality. King (1998) referred to as "the use of the self" in

which “an understanding of the experiences not only of our participants but also of ourselves as researchers constitutes a fundamental part of the research process” (p. 175). By referential reflexivity, May (1998) referred to the relations between the researcher and the persons or groups who participate in the research.

Reflexivity in this work was addressed through the two dimensions proposed by May (1998). At the onset, I conducted endogenous reflexivity to make the research methodology clear and rational. During the collection of the data, I used referential reflexivity to identify my own position within the field of the study. Throughout the research, I practiced endogenous reflexivity to open myself to my feelings and impressions with the intention to come to a reliable understanding of the social meaning of cancer recurrence from the perspectives of the participants. However, this was not a simple procedure of what the participants were telling me, but rather it implied a time of introspection. This time allowed me to critically appraise whether what I was finding from the research was a true reflection of the experiences of participants facing cancer recurrence and not an expression of my own understanding of recurrence. Introspection consisted of examining my own thoughts and feelings closely regarding the event of cancer recurrence. I attempted to deal with emerging dilemma by both writing descriptive memos on my personal reactions during the research and by discussing aspects that concerned me with my supervisors. Such an approach enhanced transparency of the data and highlighted the centrality of reflexivity through the research process.

Credibility	<ul style="list-style-type: none"> ▪ Validation of the findings with supervisors ▪ Discussion of the findings with trusted colleagues ▪ Presentation of the findings & feel-back to other researchers
Transferability	<ul style="list-style-type: none"> ▪ Use of a maximum variation sampling ▪ Triangulation of sources of data ▪ Selection of multiple sites
Dependability	<ul style="list-style-type: none"> ▪ Audit trail ▪ Full description of the inquiry process ▪ Detailed description of the research process in final report
Confirmability	<ul style="list-style-type: none"> ▪ Written memos ▪ Diagrams ▪ Reflexivity ▪ Comparison of the findings with existing evidence ▪ Refutability ▪ Constant comparative method ▪ Validation of categories with external researchers

Table 6. Procedures to ensure rigour of the study

TRIANGULATION OF DATA SOURCES AS APPLIED TO ENSURE RIGOUR

Triangulation is a strategy that limits personal and methodological biases and enhances the quality of a study (Mays & Pope 2000). This is because it helps in the construction of social meaning from how participants conceptualise a phenomenon. Besides, the same phenomenon is looked at from different angles, contributing to in-depth understanding of the nature of the event under study. Simultaneously, the triangulation of sources of data results in better understanding of deviant results or negative cases and subsequently ensures a more comprehensive integration of the emerging theory (Pogson *et al.* 2002).

The aim of this research was to obtain full understanding of the participants' experiences of cancer recurrence using an inductive approach. The convergence of families' and professionals' perceptions of the meaning of cancer recurrence might contribute to the development of a theory, which was intended to explain the main conceptual meaning of cancer recurrence.

VALIDATION OF TRANSLATION

There is agreement in research that quantitative instruments need to be checked for validity and reliability before they are used in a new context from the one they were developed for. This is justified by extensive literature on the issue of translating tools for use across cultures (Cella *et al.* 1998, Fumimoto *et al.* 2001, Karasawa *et al.* 2003, Montazeri *et al.* 2003, Serra-Prat *et al.* 2004). Few studies, however, are available on the problem of translation on the validity of qualitative data in Social Science research (Kapborg & Berterö 2002, Twinn 1997). This scarcity of information may make researchers think that the thoroughness of qualitative research is not as important as it is in quantitative work, which is incorrect. Researchers doing qualitative work need to demonstrate that the reality of the participants is as stated and described in their report. This evidence can be inconsistent if translation is not thorough enough. It is therefore advisable to check validity of the translation of qualitative transcripts, as we would test an adapted questionnaire in the target country (Fuentelsaz-Gallego *et al.* 2001).

Translation is defined as “a written communication in a second language having the same meaning as the written communication in a first language” (WordIQ.com 2005). In that sense, translation is not only transforming words from a language to another but it implies adapting meanings to a specific culture (Esposito 2001). This is in agreement with the aim of this study, which was to provide a comprehensible interpretation of the concept of cancer recurrence from the perspectives of Spanish patients, their families, and the nurses who cared for them.

In an attempt to verify the accuracy of the English version of the data, I translated three interview transcripts. The reason for choosing three transcripts was that this allowed me to have a translated version of each group of participants in the study. I chose to translate the second set of interviews because of the rich descriptions of the experience of cancer recurrence from the patient and family members. Though guidance showing the process of cross-language interpretation can be found (Larson 1998), I found it difficult to follow because direction of translating was fragmented and mechanical. However, I applied recommendations such as the importance of being aware of the contextual meaning when translating (Larson 1998).

The way I translated was through a mental process which consisted of first reading the Spanish transcripts, understanding what words meant, reflecting on what the participants' descriptions were telling me (*I could recall the participants' words because I conducted the interviews myself*) and finally reconstructing the meanings of the descriptions in the English cultural context. I used the Oxford Spanish Dictionary to translate words that I did not know in English. When I found it difficult to interpret some extracts, I went back to the original tapes to listen to them. This helped me to remain in the cultural context of the participants, so I could develop a more accurate description of the individuals' situations. Certain words, however, because of the way in which they were phrased, might have very different connotations for another culture. The difficulties inherent in translating words and meanings developed in one language into another are well-known (Esposito 2001, Navarro & Barnes 1996). When words did not have a meaningful equivalent in English, I wrote the Spanish word in inverted commas. Besides, I paid special attention to making difficult sentences as clear as possible. It is recognised that spoken language can be very ungrammatical, making translation more difficult. The use of brackets in the translated quotations also enabled me to portray the participants' personal experiences, silences, gestures, as well as the scenes that were not reflected in the audiotapes.

Once the interviews were translated, I checked the spelling and grammatical accuracy with Microsoft Word Processor. In addition to the linguistic translation

process, I found it relevant to check if my translation made sense for a native English person. My two supervisors who were English native speakers revised a reading of one of the translated interviews. Though there were sentences that had to be changed to clarify meaning, overall the English version was comprehensible. Following the steps above allowed me to verify the quality and credibility of my interpretations. If we consider that other studies using an interpreter have reported difficulty in achieving validity because of the complexities of finding a person with linguistic abilities who was trained in the research field (Kapborg & Berterö 2002), I believe that my interpretation, though time consuming and intellectually challenging, is a positive point in this research. My experience of having completed a master programme in English and having skills in research qualified me to undertake this work.

Although I did not plan to give a professional translator all the quotes from the participants used in this study because, as mentioned above, my translations were sufficiently accurate, I did it. This was possible because I received a grant from the Government of Navarra to conduct this study. In addition, I believed the quality of this work would be enhanced in terms of linguistics. The same translator also conducted proofreading of the whole thesis.

Ethical considerations

Before embarking on research with people, one must go through a series of ethical steps, including reflection on the potential damage or threat to the participants, ethical approval from a local or multi-centre Ethics Committee, informed consent, anonymity, and confidentiality of the data. These ethical considerations, in addition to ethical issues with families and nurses, were explored before and during this research.

ETHICAL REQUIREMENTS BEFORE COLLECTING DATA

BENEFITS AND RISKS OF THE STUDY

Since qualitative research is exploratory in nature, the benefits may not be apparent at the beginning of the study (Raudonis 1992). This fact makes it more difficult for qualitative researchers to set out the potential benefits of their research. In the context of this study, it seemed ethical to hear families' voices in order to gain knowledge that would contribute to an improvement in the quality of care for the individuals living through and with recurrent cancer. This study might also be useful in that it might give participants the opportunity to express their feelings and to be listened to. Indeed, two family members in this study (in family 10 and family 13) thanked me for listening to them.

The decision to include nurses in this study was based on the assumption that having the views of three different groups would explain "the truth" more deeply than using only one type of interviewees. In addition, relatively little work has been conducted on cancer nursing (Cohen & Sarter 1992) and there is a lack of knowledge on the experiences of nurses in cancer recurrence. Hence, it seemed worthwhile to add new dimensions of the concept of cancer recurrence by introducing the view of nurses in this research.

Difficult life situations and transitions are examples of sensitive topics in nursing which need special ethical consideration (Cowles 1988). Discussing sensitive topics, such as the illness of one member of the family, might generate anxiety in the interviewees; this requiring considerable attention from the parts of researchers (Johnson & Plant 1996). Cancer recurrence was related to as a crisis that might cause suffering and distress to those people who faced it (Cella *et al.* 1990, Mahon *et al.* 1990, Morse & Fife 1998, Rawnsley 1994). Thus, risks of emotional distress could emerge as a result of the interviews with families. Individuals with recurrent cancer and their significant others were assumed to be particularly vulnerable, and therefore the participants might be harmed during the interviews, not physically but possibly emotionally or psychologically. As early as in the initial phase of the research design,

efforts were made to guarantee the protection of the participants' rights, which were self-determination, privacy, anonymity, confidentiality, and protection from discomfort and harm (Arminger 1977, Beauchamp & Childress 1994, Holloway & Wheeler 1995). These rights were treated in this research, as I present next.

REQUEST FOR ETHICAL APPROVALS

The process of starting data collection meant carrying out four formal steps before carrying out the interviews: (1) getting ethical approvals; (2) receiving permission from the Director of the University Clinic and the Director of the Public Hospital; (3) receiving permission from the Directors of the Oncology Departments; (4) and acceptance from the nurse managers of the four settings. In this section, only issues of ethics are presented. For details on the process of approvals from the two centres, see Appendix 4.

Once the design of the study was ready and after a proofreading of the complete research proposal by a nurse lecturer, the document was sent to the Ethics Committee of the University Clinic. The proposal included three information sheets (one for patients, one for family members, and one for nurses), three informed consent sheets, and three socio-demographic sheets. Each of the information sheets contained a general description of the study and its ethical aspects, my name as the researcher and my contact details. The informed consents gave information on the ethical aspects of the research and left a space for the signatures of the participants and the researcher. The socio-demographic sheets contained blank spaces to fill in the data of participants regarding their status, age, medical history, and other data relevant to the study (Appendix 5).

In reply to the formalised electronic application, the Ethics Committee asked me for two minor modifications. The changes consisted of specifying the areas discussed during the interviews in the information sheets, making clear in the informed consents that participation in the study was entirely voluntary and that withdrawal

from the study would not affect care in any way at any time. A new version of the document was sent and ethical approval was obtained in September 2003.

I contacted the Ethics Committee of the Public Hospital to ask for ethical permission to conduct the research in the second centre, named the Public Hospital in this study. The secretary of the Committee informed me that it was not necessary to apply to a second committee as I had already approval from a committee of the region. Despite having received both written consent from the Director of the Hospital and verbal consent from the Director of the Oncology Department of the Hospital, I did feel anxious. Therefore, I wrote again a letter to the Ethics Committee of the Public Hospital explaining my concerns and requesting written permission. Finally, I received its written approval.

INFORMED CONSENT

Informed consent was addressed through the provision of information sheets and consent forms to be signed by participants. I also informed participants that their involvement was voluntary and they could withdraw from the study at any time. Apart from these procedures, I adopted the use of process consent, which consists of a re-negotiation (of the agreement to participate in the study) at different stages of the interaction between the researcher and the participant (Beaver *et al.* 1999). A cancer crisis could have contributed to the vulnerability of patients and families (Rawnsley 1994). Interviews could be very emotionally charged leading participants to reveal information that they might not have disclosed if they were not in that situation. To avoid this situation, I planned to ask participants at the end of the interview if they maintained their agreement to the study. Following this approach likely could reduce the sample size (Raudonis 1992). However, participants' wellbeing took priority over the interests of the research.

ANONYMITY AND CONFIDENTIALITY

To enhance anonymity, I used codes to replace the names of the interviewees. For instance, interviews were coded numerically according to the order they were conducted. Furthermore, every effort would be made not to identify the participants from any report published about this research. As patients and family members were interviewed separately, information conveyed to me was confidential and was not disclosed to anybody, including other family members.

To ensure confidentiality of the data from the participants, the written records were stored in a secure filing cabinet and in my personal computer. Certainly, no details from the participants were disclosed to any third person without the individual's consent.

ETHICS WITH PARTICIPANTS THROUGH THE RESEARCH

Collecting sensitive data such as suffering of families with cancer can be challenging for researchers (Johnson & Clarke 2003, Northouse *et al.* 2006, Rager 2005). Using a flexible design that allows for the construction of relationships with participants has been found important when addressing sensitive topics (Daly, 1992). This is because “qualitative researchers are in good position to access the private meanings of families” (Daly 1992, p. 5).

As early as the initial planning phase, I considered whether to continue interviewing if I realised that participants were highly distressed. If this occurred, I would invite the interviewee to stop the interview. In addition, support from healthcare professionals would be proposed if participants required it. Safeguards, which consisted of offering support from the nurse-managers of the four settings where the study was carried out, were planned beforehand to deal with any participant who experienced great distress.

During the interviewing process, because I anticipated that discussion on the impact of recurrence could provoke emotional distress to individuals, I approached the families with respect and compassion. I acknowledged that the interviews would

reveal intimate details about the respondents and that sharing thoughts and personal concerns could be distressing. Thus, every effort was made to ensure anonymity and maintain comfort of the participants by being sensitive to the families' concerns. I also spoke first with the nurse in charge to ensure patients would not be contacted if they were likely to be very distressed.

In addition, I was aware of how emotionally laden the words "cancer recurrence" could be due to the link in many people's minds between recurrence and poor prognosis. I also found it probable that families did not know the medical definition of recurrence. Hence, to avoid possible distress caused by the term, I did not use it during the interviews with patients and family members. Other words, such as "second cancer" or "the return of cancer" were used.

Finally, I acknowledged that recruiting participants for this study would have been easier if I had worked in the settings where data were collected. However, I realised that potential participants would be familiar with me and they might feel obliged to participate in the study. To prevent this situation, I decided not to practice in the settings selected for this research.

Summary

This research presents a grounded theory study of the social phenomenon of cancer recurrence within the Spanish context. The views of patients, their family members, and nurses were investigated. In the following three chapters, I will present the findings of this research.

CHAPTER 4

“AGAIN” – WHEN FEAR OF RECURRENCE BECOMES REALITY

I think that everyone thinks they are under the threat of it [cancer] happening again; but between thinking it might happen again, and it[recurrence] really happening, that's very different (Nurse 7)

Introduction

In this research, three social actors, namely patients, family members, and nurses played a significant role in the experience of cancer recurrence. Excerpts from the three groups are used in this work in an attempt to contribute to a psychosocial understanding of the phenomenon cancer recurrence. In the next three chapters, I provide an understanding of the meaning of a cancer recurrence through the interpretation of the participants' words. The chapters are organised into concepts, main categories, and subcategories that are interrelated and interdependent. In addition, the categories are related in time and link with the past, the present, and the future because the analysis of the data showed time to be important in the experience of cancer recurrence. Therefore, to make the temporal dimensions of recurrence that were characteristics in this research clear, some of the emerged categories are named using elements of temporality, such as “again” and “it's too long”. The categories in inverted commas have been labelled with the participants' own words for two reasons. First, using “in vivo” codes enhances credibility of the emerging categories

(as described in chapter 3). Second, drawing on the respondents' words meaningfully summarises their understanding of the experience of recurrence.

Chapter 4, "*Again*" - *When fear of recurrence becomes reality*, illustrates the impact of recurrence on the lives of cancer survivors and their family members. Chapter 5, *Demoralisation as a response to the suffering of recurrence*, refers to the nature of suffering that the families experienced after a diagnosis of recurrent cancer. Demoralisation was identified in the data as a form of suffering that resulted from repeated crises with cancer. Time was found an important factor that provided the background of suffering in recurrence. Chapter 6 named, *Rebuilding morale in the experience of recurrence*, designates a turning point for the families that involved a readjustment to the illness. The experience of nurses about caring for patients with recurrent cancer and their families is also examined through these three chapters.

In the current chapter entitled "*Again*" – *when fear of recurrence becomes reality*, I present four main categories that have emerged from the data. These are: *fear of cancer recurrence*, *the impact of recurrence on cancer survivors and their family members*, *suffering of the families*, and *nurse encounter with families after a diagnosis of recurrent cancer* (see Figure 7). Patients and family members had a mutual influence on each other's experience of recurrence; each affected the other as symbolised with a two-way arrow in Figure 7.

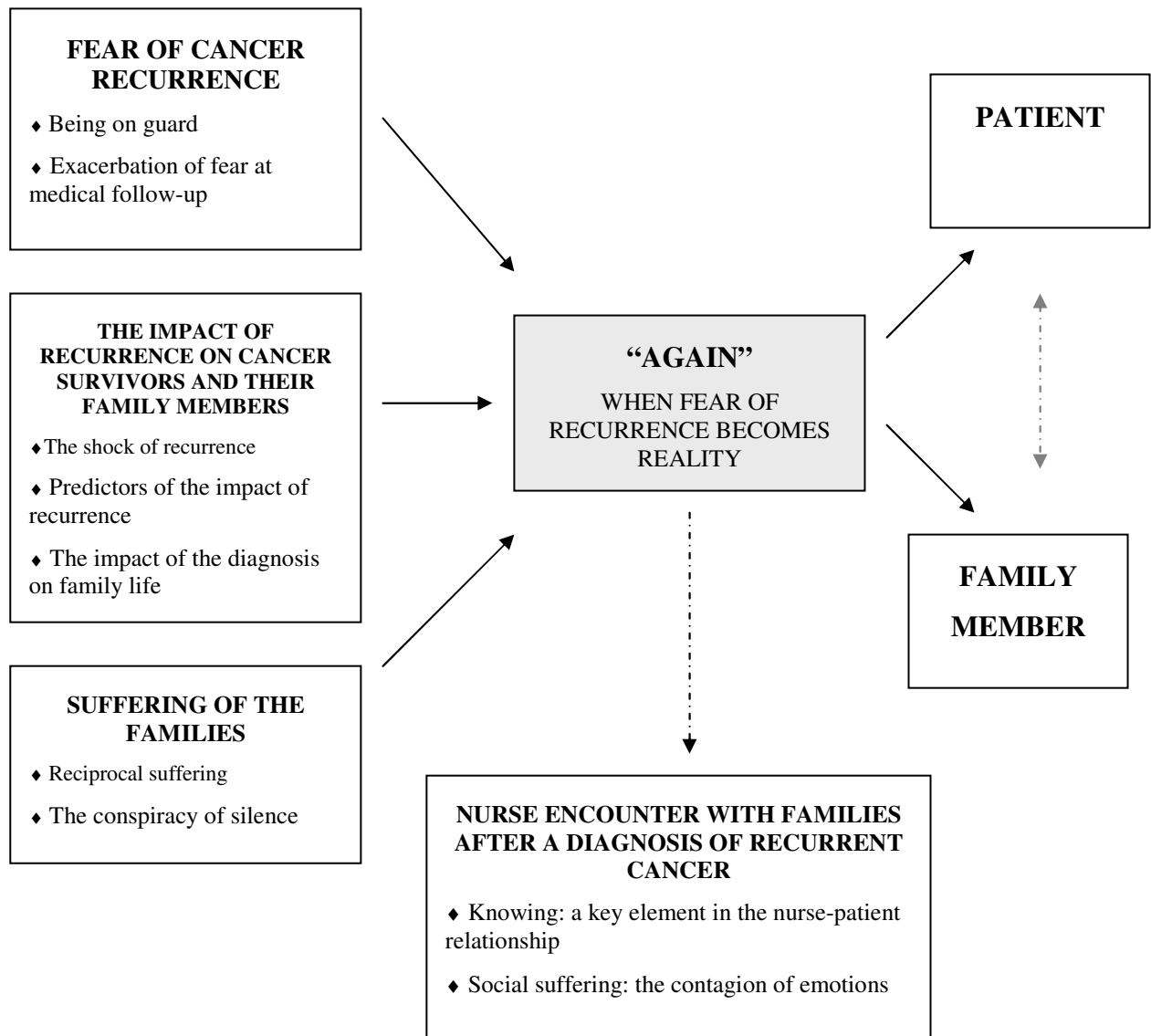


Figure 7. Psychological impact of recurrence on the families and nurse encounter with families after a diagnosis of recurrent cancer

Before proceeding, it is important to clarify the meaning of the term “again” in the context of this research. The title of this chapter is directly linked to the common response of the participants when I asked them to describe the meaning they attributed to a cancer recurrence. All the participants, including patients, relatives,

and nurses, used the term “again” to refer to recurrence. For example, one of the nurses described recurrence in the following way:

Another relapse means again, going through all that again, chemo again, it was so awful, it's as though they [patients] don't understand, "but I thought I was cured?" (Nurse 12)

The characteristic of “again” occupied an important position in the definition. The nurse repeated the word three times to emphasise a return of an unpleasant and shocking episode. Another definition of recurrence was described as follows by a nurse who had worked for 14 years in cancer services:

At a physical level, well, the appearance of a tumour again, and then well, at a psychological level, it's a blow, a terrible blow, because they think it's all over and suddenly, oh dear! a check-up and there's something there (Nurse 14)

This definition brings with it the idea that recurrence is divided into two basic elements. First, there is a medical aspect that involves the physical return of the disease and a psychological element that comprises the emotional impact of being informed that cancer has come back. Although the two definitions have different foci, they coincide with the experience of recurrence being distressing. In addition, both definitions capture a meaning of recurrence as a look back on the experience of suffering and hardship of chemotherapy. The term “again” articulated a succession of events that surfaced after a diagnosis of recurrence and showed a relationship between the past and the present. In other words, the concept was used as a linguistic symbol to describe the impact of cancer recurrence on the participants. “Again” symbolised a beginning and a continuation with cancer; it represented new suffering for the families and it implied a reencounter with health services.

Fear of cancer recurrence

This category presents descriptions of the participants who spoke retrospectively about the fear of recurrence. The end of treatment entailed a time of uncertainty about the future because of the unpredictability of cancer and the insecurity of treatment effectiveness (these aspects are discussed in detail in chapter 5). Fear of recurrence occurred when patients had finished treatment and entered the stage of remission. Having looked back over past experiences, the patients and family members reported they were aware of potential recurrence. This concern made the families feel distressed due to the fear of having to face cancer again. In other words, fear developed as a result of the threat of new harm.

Two common reactions to fear of cancer recurrence were identified in the data. These were subcategorised as *being on guard* and *exacerbation of fear at medical follow-up*. The two responses that are developed next, provide a background for understanding the extension of the fear of recurrence that the families experienced after end of treatment for primary cancer. Furthermore, the data may be useful to gain broad knowledge about how cancer survivors and their family members experienced fear of recurrence.

BEING ON GUARD

The phenomenon of *being on guard* occurred during remission and survivorship. It described how the patients devoted constant attention to their health condition and how their family members were concerned with their loved ones' wellbeing. The situation of vigilance is captured in the next extract from a breast cancer patient who had survived 14 years before she was diagnosed with her first recurrence:

Last October, it turned out that I have it again. Maybe what I have to do is never lower my guard; never say I'm completely cured (Patient 1)

The data above show the patient's concern about "being on guard". During the interview, the woman reported the battle of cancer was never completely won and that was why, even when she was a long-term cancer survivor, she worried about the possibility of recurring cancer.

An important issue derived from maintaining one's guard could, however, be the intrinsic suffering of patients. When survivors experienced minor symptoms of pain or discomfort after treatment ended, insecurity arose and thoughts of a possible recurrence emerged. One of the patients, who had survived 8 years with no evidence of breast cancer progression, explained her continuing fear of recurrence during survivorship as follows:

[I've always been afraid] because first you say, "I have to put up with the treatment, I have to get strong", I mean, you try to get on with it. And get on with it as well as possible. But when it's all finished, you feel insecure. I always say that it affects you psychologically...I feel it's something you're left with, it scars you forever (Patient 5)

From the above extract, it can be suggested that the woman considered herself to be under a constant shadow of anxiety related to the fear of recurrence. The use of the word "forever" shows the idea of duration. The fact that fear was omnipresent in the woman's mind can suggest that the fear of recurrence was an enduring experience for this patient. Other interviews with patients emphasised the idea that fear of recurrence remained over time:

There's always that doubt. Although obviously, it's hard to forget it [fear of relapse]. I mean, although you don't do it on purpose, it often comes in my dreams (Patient 6)

The patient described fear of recurrence appearing in her dreams, despite her position against thinking that cancer could reappear. The possibility that cancer may recur seems to give an unconscious awareness for this woman who further reported that fear gradually lessened as length of disease-free survival increased.

The type of primary cancer appeared to influence the intensity of the fear of recurrence. For example, pancreatic cancer was identified as associated with increased probability to recurrence, resulting in patients with this type of cancer being more aware of such possibility, as shown by a patient with local pancreas recurrence:

You are waiting and watching all the time, waiting and watching every day, and now [after the relapse] well, that's what it's like, a person who has a disease like this is waiting and watching out for it [cancer] and that at any moment it may develop (Patient 11)

Like patients, family members worried about the possibility of a relapse. The wife of a patient who was diagnosed with a recurrent cancer of the pancreas reported being on her guard because doctors told her that the disease could recur. As she explained:

You're always uncertain because it's a continuous... I mean, every morning I remember to ask, "How are you?" Always "How are you?" or "How're things?" Always expecting to be told, it hurts here, or it hurts there, hoping he wouldn't say it, but always thinking that anything could happen to him (Spouse 7)

The above extract shows that the possibility of recurrence could produce so much fear that some families experienced of a period of restlessness and excessive preoccupation. The fear of a recurrence could be omnipresent in some participants' minds. The constant thoughts related to fear of recurrence could control some families' lives and prevented them from living normal life. For some patients, especially patients with recurrent pancreatic cancer, fear of recurrence was high. These findings are consistent with other studies that evidence that some type of cancers, such as ovarian cancer and pancreatic cancer, may cause increased levels of uncertainty because of the advanced nature of the disease at the time of diagnosis and an increased probability to recurrence (Howell *et al.* 2003). It has been reported that 70% to 80% of women with ovarian cancer experience a relapse of their disease following first-line treatment, and that the prognosis for the women is poor (Latorre *et al.* 2002). The dismal survival statistics likely increased fear of recurrence in the

patients and the family members facing these types of cancer, resulting in a more prominent fear in these families.

As discussed earlier, fear of recurrence decreased for some patients as they moved on through survivorship. The proximity of medical follow-up, however, reawakened the fear and often provoked great distress in both patients and family members, as I describe next.

EXACERBATION OF FEAR AT MEDICAL FOLLOW-UP

Medical visits were a stressful time for most of the families. Different emotions reawakened before routine follow-up. Some of the patients reported being anxious because they remembered the time they were diagnosed with first tumour. As one of the patients reported:

I was nervous, because it's been six years since the last time. OK, at the beginning I was also more nervous. Well, whenever you come in here [hospital], when you come in through the door you remember everything (Patient 6)

Entering the hospital brought the woman back past experiences with cancer and many unhappy times. This was because of the recurrent suffering the woman had experienced as a result of three diagnoses of cancer. When I interviewed her, she was finishing treatment for a second relapse and she was very positive about the future. However, when she had her first relapse about 6 years before the interview, her life was seriously threatened due to the tough therapy she received and the location of the metastasis. The woman added that the time of follow-up was stressful not only because of memories of suffering due to cancer and treatment but also because of the unpleasant experiences related to medical examinations.

Fear might be experienced days or even weeks before the follow-up appointment. At times, the fear of having a check-up was so intense that physical symptoms, such as pain, could arise. As one of the patients described:

Every time I came for a check-up or maybe two months before, began if I had an ache anywhere. Feelings of pain that maybe I didn't have (Patient 5)

The great worry of recurrence led this woman to interpret sensations as signs of illness. Such behaviour may be partially explained by the results of a research in psychology health that has found that cancer patients who perceived tamoxifen-induced symptoms during remission of illness experienced trait anxiety that was associated with a tendency to activate vigilance to symptoms, attribute symptoms to health threats, and greater fear of recurrence (Cameron *et al.* 1998).

Attendance at follow-up visits created an undue psychological burden because the patients feared being informed that their cancer had recurred. A nurse corroborated the emotional distress due to anticipatory fear of recurrence in this way:

People are usually scared of "one more time". Back to the clinic, for what? For them be told again they've got the disease (Nurse 2)

Fear might also be experienced as a result of memories of past check-ups. The following extract illustrates the experience of a patient who had been informed twice of a diagnosis of recurrent cancer during a periodic follow-up. During the interview, the woman reiterated always being frightened. When I inquired about whether she was able to enjoy life in between follow-ups, she replied:

Yes, but I'm afraid, always afraid.

CGV: Afraid of what?

That the time will come for [the check-up], because they've always found it in the check-ups, I'm afraid during the time between one check-up and the next (Patient 2)

This extract suggests that when reappearance of the illness had been informed during a past check-up, the patients might identify medical appointment with the possibility

of a recurrence. It can be said that when the participants linked the two events together, intense fear of check-up surfaced. For the above patient, having medical visits was so extremely upsetting that she considered withdrawing from them in the future:

I think I'll never come back, because every time I come for a check-up they find something. I come in feeling well, I've been living my normal life, and when I leave here I've turned into a freak [silence] so I'm thinking about not coming back for any more check-ups (Patient 2)

Similar to the above patient, her spouse felt highly distressed when his wife had to go for a check-up. This is exemplified by the emotive words of the spouse when I asked him whether fear disappeared in-between check-ups:

The misery never goes away, and at every check-up. For me coming here is horrible, for her obviously, but for me too (Spouse 2)

The experience was distressing for this spouse because he feared that cancer would come back again or the disease would have progressed. He proceeded:

I feel terrible. I'm going through it just like her. I'm miserable, scared of coming here. She's afraid, I'm more so, the same or equally. Terror, terror, terror...fear. "You're very well, come back in four months", you feel so well going home, but two months later it's that thing again and it's horrible (Spouse 2)

The above quotes made by the same spouse suggest that he understood recurrence as related to the uncertainty of the progression of the illness. There is also evidence that the spouse experienced intense fear before attendance at the next check-up, an emotion that he concealed so as not to worry his loved one. It is worth noting that most of the family members hid their emotions from the other members of the family, as I shall present later in this chapter. Further, these findings suggest that the family members might share the emotional state of fear.

Other patients, though anxious, reported their wish to continue follow-up. The next extract made by a woman who had been disease-free for 13 years before she had her first relapse captures the benefit of follow-up:

Two years ago, I had a relapse of the disease, at a normal check-up. An annual one I had, and I thought I was well, a routine check-up, and well, they told me that I had it again... But really I had no symptoms, a routine check-up. The plan was to come because I have always liked to have a routine check-up, and thank God, because if I hadn't come, because I truly didn't feel ill (Patient 1)

This woman considered follow-up important because it was a way of detecting the return of the disease that could go unnoticed when there was no symptomatology. There was an emphasis on the idea that cancer could come back at any time. Its reappearance could be insidious, thus the woman felt sheltered if she attended follow-up on a regular basis. She continued to report being alert about her health since she was first diagnosed with cancer fifteen years ago. Even though doctors had told her that she was cured of cancer as she had survived for more than 5 years without evidence of the disease, she never stopped having annual check-ups.

Some patients, even when being perceived by health services as cancer survivors, felt reassured by having routine follow-up. Fear of recurrence seemed to continue, as the disease was believed to grow silently over time and even during long-term survivorship. Besides, being told that there was no progression of the disease was a source of relief for the patients. The comfort that patients gained when they received good news about their illness created a need to continue attending routine follow-up, although feelings of anxiety came back at the next visit.

In summary, both the fact of being on guard about physical symptoms and the worry of follow-up because of what might be found caused great fear in the patients and their family members. Because participants' words are often richer than researchers' interpretation of the information, I would like to conclude this section and introduce the following using the next quote that captures the feelings of a woman who moved on from fearing recurrence to having cancer again:

And then it's back for the second time and, of course, you say now I've got it. And I think how silly I was when I believed all the time that I was scared and had those things, you ask yourself what the suffering was about, if really when you have it [recurrence], is when you will suffer (Patient 5)

The impact of recurrence on cancer survivors and their family members

The psychosocial impact after first cancer has been widely described in the literature. Within palliative care, authors have advanced knowledge of the insights of early studies of the impact of death on distress and suffering. However, it is particularly as part of the effort to have a complete picture of the experience of living with cancer that I describe the psychosocial impact a cancer recurrence has on patients and their family members. The following section explores the responses of the participants to a diagnosis of recurrent cancer. The new diagnosis was found to profoundly affect psychological aspects of the patients themselves and their family members.

THE SHOCK OF RECURRENCE

Both the patients and their family members reported emotional impact after being diagnosed with recurrence. They described this time as being difficult and devastating. The next statement captures the view of many relatives after their relation was diagnosed with recurrent cancer:

You're getting better, and then the moment comes, and you hear, "Watch out, this is bad", well, the change is hard, very hard... Very hard, it's as if the house was falling in on you (Spouse 3)

Many participants reported signs of shock and frustration as an initial response to recurrence. In the following comment, a 24-year-old daughter explained her anger after she knew that her mother had cancer again:

What did I feel? [sighs] Pain, anger, helplessness, anxiety... I can't explain it, it was like, you want to know why, more than anything else why. Why my mother? Why? But anyway, that was at first, I think that then I lost heart completely (Daughter 1)

While trying to make sense of suffering, this daughter expressed her anger in the form of impulsive questioning. Her words illustrate well how painful it was for her to know that her mother had cancer again. In the continual questioning, she sought to find meaning in the situation in an attempt to decrease her suffering.

As discussed in the introduction of this chapter, time was an important feature in this study. Time took on a new meaning after a diagnosis of recurrent malignancy. This was because recurrence added to previous suffering. The families expressed their views of the long-term nature of cancer articulating words like “time” and “long”, as shown below:

When I got the news, the same thing again, one more time, it's been a long time already. You don't know when it's going to end, or how, then it's too long (Daughter 2)

I can't say I'm better; I know this is long-term (Patient 15)

Nurses, however, employed the word “chronic” or “chronic illness” to refer to the enduring nature of cancer:

Nowadays, if these things are caught in time, a patient diagnosed with cancer may be considered as a chronic patient, like a diabetic (Nurse 9)

They know more, then they talk more about their prospects... this happens when they have recurrences, when you see them here turning into chronic patients (Nurse 11)

While I was alert to the ways in which the families described the impact of recurrent cancer, I was also aware about the ways in which the families expressed their suffering. The impact of recurrence is illustrated in the next passage from a spouse of a woman who had had two relapses:

That little black 2-centimetre mark appears, a nodule. Imagine what it's like for a woman who has gone through so much, and for us. It's something you can't, I think it's such an intense thing that one lives at that moment (Spouse 2)

The above extract highlights that what became most distressing in this spouse's experience was not so much the pain of his affliction, but rather the situation of enduring suffering. In an attempt to understand the intensity and type of distress that the families experienced during different diagnoses of cancer, I asked the families to speak about their impact after first diagnosis of cancer compared to the impact after recurrent cancer. Some of the responses are shown next:

Well, difference, this is much harder because a second time... The first is hard; well the second is even more. I think a second, because as it is a relapse I think it's far worse than the first when you say, "Well, we'll see". In the first, I think you feel stronger (Patient 5)

The first time is a terrible blow ... but you think that maybe it's not cancer even though it's been diagnosed or it's may be very small and that, after all, they cut, inject, operate and that is that. It very different, on the one hand terrible distress but you are much more hopeful (Patient 10)

Learning that cancer had come back was for most of the families more devastating than hearing that they had cancer for the first time. This was largely found to be due to the enduring experience of cancer, uncertainty about the future, and hopelessness (as I shall describe in the next chapter). Indeed, hope had an important place in recurrence. Patients reported a perception that a recurrence was harder because hope diminished. Family members similarly described hopelessness after recurrence:

The first time was very hard, and the second, well, it's hard too, but it isn't that we are more hopeful than the first time, on the contrary in fact (Spouse 7)

Generally, nurses also identified the experience of recurrence harder because of hopelessness:

The first [time] they have a bad time, but the second is harder for them. They are more frightened; they think they can't go on, that the second time they have less chance (Nurse 5)

Additionally, the impact of a recurrence seemed to be tremendously difficult for the families because recovery from cancer was uncertain. This time of vulnerability could mean that the disease was not curable anymore but it had to be controlled to prevent progression. Therefore, most of the families found recurrence harder because of a combination of emotions based on initial shock followed by a crisis of uncertainty about what could happen. Other factors seemed also significant on the impact of recurrence on the families, as is described next.

PREDICTORS OF THE IMPACT OF RECURRENCE

Time seemed central in the way the families received the diagnosis of recurrence. Different emotional reactions were found if the patients were short-term survivors of cancer and long-term survivors. For example, a nurse explained how the impact of recurrence might be different after having survived cancer for many years:

It's not the same to have to face up to a relapse after six years disease-free as after a short time...they [patients] have been able to enjoy those six or seven years, that time without the disease...so, they can face a second fight with a different courage (Nurse 9)

These results are consistent with other descriptions made by nurses that linked benefit with long-term survivorship. For example, a nurse observed that long-term

cancer survivors usually were more optimistic compared to short-term survivors. As the nurse stated:

These people [long-term survivors] come with high hopes. High hopes in the sense that they say: "They gave me chemo before, and here I am 10, 15 years later", they see things very differently from those who have a quick relapse. They look forward to a long future, that is, they look back on their previous experience (Nurse 13)

Having survived for a long period of time without evidence of the disease was important because it gave hope that this would be repeated after completion of treatment for recurrent cancer. In contrast, being diagnosed with cancer soon after the end of early treatment might bring negative ideas about a recurrence, such as endured suffering. Frustration that cancer had spread so fast is shown in the following extract from a patient who had relapsed 15 months after first treatment:

It was a terrible blow I got when I found out it was back so quickly; I haven't got over it yet (Patient 3)

The patient might have hoped that cancer was cured after the first treatment. Yet, she found cancer had come back, leading her to experience feelings of shock and distress.

However, a nurse described an opposing view about the relationship between being a long-term survivor and the impact of recurrence:

When they've had several years [of survival], it seems that they have forgotten about the illness, and they say, "Well, it's under control". They seem very surprised when they've been like that for many years (Nurse 14)

According to this nurse, having survived for a long period after cancer appeared to be associated with negative outcomes in that the patients might think they were cured. This observation was not limited to this nurse but a long-term cancer survivor also remarked it:

I've had 10 great, marvellous years, at every level; health, family, the four of us so happily together at home, and this has changed me so much that it's worrying (Patient 1)

The woman reported it was difficult to realise that she had cancer again after having enjoyed life for so many years after the first cancer. The notion that recurrence could be developing in any time, even after 10 years of survivorship, is captured in the above quote. The findings further suggest the overwhelming sense of vulnerability, at any time, to a diagnosis of recurrent cancer.

Regarding the circumstances of the disclosure of a recurrence, there were emotional differences between patients who were experiencing pain or discomfort previous to the diagnosis and those patients who had no symptoms and who were diagnosed after a routine examination. For example, the patients who presented symptoms prior to the diagnosis of recurrence (patients 4, 5, 7) seemed to experience great levels of distress due to the fear of cancer. This finding is consistent with research suggesting that common physical symptoms may increase cancer fear by focusing attention on cancer and precipitating fear of cancer (Cameron *et al.* 1998). Moreover, high levels of fear of recurrence have been associated with poor emotional wellbeing and mood disturbance (Ullrich *et al.* 2003). In contrast, the patients who did not report any suspicious symptom were greatly surprised when they were told that cancer had recurred in a routine check-up. This is reflected in the following extract:

It's not right, not right, because I feel well, great. It's unbelievable, absolutely unbelievable (Patient 11)

The moment of a diagnosis of recurrence was described as shocking in the above quotation. The word “unbelievable” draws on this shock. It was not only necessary to be on the lookout for the growth of cancer all of the time, but it seemed that the insidious recurrence reinforced the view of cancer being unpredictable.

Additionally, a nurse stated that age of the patients would appear important in the way the family received the diagnosis of recurrence. She explained:

Then it depends if it's a young person or someone old. An older person lives it in a completely different way. A 70-year-old who thinks he's going to live 10 years more, this means a lot to him. However, for a 30-year-old, 10 years is not long. It's very different (Nurse 13)

Although the degree to which individuals experienced distress was personal and unique, the above extract emphasises the idea that younger patients with a recurrence seemed to experience greater impact compared to older patients. Such observation was attributable to the natural fact that younger patients would likely have a higher life expectancy if cancer did not appear, compared to older patients who are likely to have a lower life expectancy. These findings are in line with other research that reported that compared to older women, younger women had poorer psychological adjustment to breast cancer (Vinokur *et al.* 1990).

Finally, the location of the recurrence seemed to influence on the families' experience with recurrence. The following is the description of a husband of a patient who had been diagnosed with cancer three times, highlighting this point:

Of course, it's not the same either depending on where the disease appears. Where it is in the body reflects people's reactions clearly (Spouse 6)

For this spouse, the location and extension of recurrent cancer greatly contributed to the difficulty of the experience of recurrence. His perception is meaningful given that his wife had experienced a distant recurrent cancer one year and four months after primary cancer. The patient required staying in the intensive care unit because she was very sick due to cerebral metastases. However, the patient was treated successfully for this first recurrence and she had survived for five years and three months without evidence of the disease before she was diagnosed with the second recurrence for which she was being treated. The above quote also shows that how sick the patient was judged to be, was in part based on the location of the recurrence.

Overall, there were differences between short-term and long-term cancer survivors. Patients who were diagnosed with recurrent cancer soon after the end of formal

treatment seemed to associate recurrence with an understanding that the disease had not been totally controlled. This situation of vulnerability contributed to these patients and their family members feeling there was less hope of cure (explained further in chapter 5). Long-term survivors judged recurrence to be more hopeful because they anticipated they might survive cancer again as they did before. In addition, age, number of recurrences, and location of the disease seemed to influence how families perceived the impact of a recurrence.

THE IMPACT OF THE DIAGNOSIS ON FAMILY LIFE

The diagnosis of recurrence was a moment after which life changed. The patients went from being short or long-term survivors of cancer to being patients once more. In addition, the families went from a state of fear due to the potential of a recurrence to uncertainty and distress as a result of the new crisis. Facing the reality of a recurrence of cancer required ongoing efforts and restructuring the family environment. Family life had to incorporate the family's commitments to the management of recurrence. Therefore, the diagnosis entailed a change in family organisation. After a more or less extended disease-free period, the family unit had to be restructured and members had to adopt new roles, distinct from their previous family roles.

During patients' treatment for recurrent cancer, there were modifications in the life of the family. Treatment side effects as well as hospital visits, determined the rhythm of family members' lives. The fact that patients were in treatment often increased dependency within the family. On one hand, most of the patients had to be cared for by their family members during major symptomatology due to chemotherapy. On the other hand, there is an intrinsic belief in many Mediterranean families including Spanish families that it is the family's responsibility to care for its ill relative. Therefore, it is considered natural that family members are usually responsible for the care of the patient. In this context, when a family member became ill, the repercussions for the family were important. Notably, when the patient was a mother,

the illness seemed to have a greater impact on the life of the whole family, as pointed out by a nurse:

There's a big difference depending on whether it's a man or a woman...when it's a woman, it's almost always a disaster. A complete disaster, because the whole family is out of control (Nurse 10)

When patients required care during a prolonged period, relatives might give up many of their own activities. In that sense, if the patient was a woman who had usually had responsibility for family life, the husband in the couple adopted full responsibility for the continuation of the family's life. Whereas for some of the families changes of roles were trivial, for others changes were paramount. For example, when asked about the changes occurred within the family, the daughter of a patient with three children said:

Personally, mine is radical. Really because I am the only girl in the house. So, my mother's role, I give up my normal role as a girl and take on my mother's role (Daughter 2)

The above extract illustrates the perception of the adoption of new roles within this family. The implications of these findings suggest that the illness of a family member interrupted the usual roles performed by the patients. When the patient was the mother, as presented above, the new role often consisted of carrying on housework and taking care of young children. This new responsibility was generally divided among the family members, who were often the spouses or the adult children. In the above family, the daughter had devoted her life to her family. The greater involvement of the daughter in care-giving may be partially explained by gender issues. That is, the daughter was a woman and the other members in the family were men. Although it is not imperative, there is a social tradition that manifests that women generally assume the responsibility for looking after the family. This suggestion is in agreement with studies conducted with caregivers of the elderly who are dependent (Walker & Pratt 1995).

The reorganisation of roles was not always well accepted by the patients who might feel guilty. In order to avoid this, the family members tried to run things as normal. For example, the abovementioned daughter explained how difficult the new responsibility was for her because she had “to learn everything” about housework. This included activities such as cooking, cleaning, and buying groceries. When the patient felt unwell because of chemotherapy effects, the tasks might include helping the sick member in activities of daily living, such as bathing, dressing, maintaining personal hygiene and getting around. As reported by the daughter, these responsibilities could make her feel sometimes distressed. However, the greatest challenge for her was to hide their mother’s inability to run the house from her family members.

Like the above daughter, most of the family members reorganised their lives around their ill relative. Some of them even reported their thoughts about leaving their life and focusing on their ill member, like the spouses in family 3 and 9. Feelings of responsibility to the patients were on occasion so intense that some family members experienced high levels of life disruption. Besides, excessive responsibility of caring could entail antisocial behaviour. This was noted in the case of a couple who reported having stopped “travelling, seeing friends, and everything” after they were first diagnosed with cancer. It can be said that disruption in the family’s social life and the overall loss of social activities could affect the quality of life of families negatively. Besides, the wife in the couple reported having neglected her appearance since her spouse felt ill because she did not want to leave him alone:

I can’t even have my cataracts operated on because I can’t afford even those five days because I need to be with him. He’s ill but he needs the support of the whole family (Spouse 10)

This extract shows that this spouse avoided making plans, even when these related to her health condition. Others spouses justified their behaviour as not wanting to leave their relative alone in case of unexpected outcomes.

Commitment to the patient after diagnosis of cancer might be so central as to influence choices within the family. The next quote shows how a couple's decision to divorce changed after the patient was diagnosed with cancer:

Somehow now I feel that I need and want to help him and that I've got to be there. What I mean is, even if I had or had had planned to get divorced, now I can rule it out because he needs me and there I am (Spouse 7)

Cancer might bring family members closer together. Moral duty was revealed in this instance as a gesture of responsibility to the ill family member. In some cultures, such as in Spain, families have a strong sense of duty and obligation to their ill members (Andershed & Ternestedt 1998).

Commitment to the patient was seen to be a positive way to cope with recurrence. According to spouse 9, caring for his wife made him feel happy, even if this situation included giving everything up for his loved one. This might be because it was gratifying to meet the needs of his loved one. Besides, caring for his wife seemed to reduce feelings of helplessness and enhanced perceived control over the health of his wife. Through the interview with this spouse and other relatives, it also became apparent that helping their member improved family relationships in terms of love and kindness, as I shall explain in chapter 6.

However, changes of roles might include work disruption in addition to treatment and travel costs, contributing to emotional concerns for the families. The participants who were interviewed in the University Clinic, which is a private centre, described this aspect overall. A spouse perceived having experienced so many changes during his wife's cancer journey that he summarised his perceptions as follows:

[Changes] in everything, but at very high levels (Spouse 3)

We can see from the above extract and the interpretation of other descriptions in the interview with this spouse that he felt particularly vulnerable due to the many changes that were occurring after the diagnosis of his wife's recurrent cancer. In

addition to the loss of health of his wife, he was enduring other difficulties, including financial problems, social changes, and loss of employment. Frequent hospitalisations contributed to his having to leave his work to be able to combine work activity and treatment. Whilst at the beginning of the interview the spouse showed that he was trying his best to support his wife, he reported finding changes “very hard”. In an attempt to understand the meaning he attributed to this situation, I asked him how he would define “very hard”. He explained:

Very hard is when you feel the house has collapsed: the house, the family, work, etc. Let me tell you, last year I was here 3 months, I sold my business, I gave up work, sold every thing I could and started again... So it's not just an economic subject, but personal too, we have a child and changing all that is hard, very hard. Psychologically you have to be very prepared; I think I'm not although I'm getting on with it (Spouse 3)

The data evidence the profound impact that recurrence had on this family. Many of the sentences that the spouse used, like “that is hard, very hard” indicated the intense suffering he was experiencing due to cancer and its treatment. The use of the metaphor “you feel the house has collapsed” emphasises on the idea that recurrence could be devastating at different levels, including “family”, “work”, “economy”, and at a “psychological” level. The interview with this relative was especially enriching, not only because of the verbal description of his experience, but also because of non-verbal communication. During the interview which lasted 45 minutes, the spouse showed his suffering through the sad look in his eyes when he described the devastating changes in his life. Besides, his trembling voice when he spoke about his wife’s condition and his sad voice when he referred to his 10-year-old son reflected how difficult reappearance of cancer was for him. It was thus an accumulation of factors that made the spouse feel distressed and out of control because of the overwhelming family situation.

A nurse concurred with the above spouse, arguing the great impact of cancer on families who had to receive cancer treatment far away from home:

As this [hospital] is a reference point for people from many areas...they have to come to the other end of Spain, and all that implies of disorganisation for the family, economic cost, it's a mess (Nurse 9)

It is clear from the nurse's statement that receiving treatment away from the patients' home area led to separation of patients from the rest of the family, resulting in significant emotions. This finding is consistent with literature that evidences that the fact of being treated away from family support and social networks may increase psychological distress in patients (Fitch *et al.* 2003, Payne *et al.* 2000). In addition to this, the above quote from the nurse suggests that when the cancer patient was a mother, being away from home was more distressing for the family because of organisational difficulties. These findings have implications for practice in that health professionals need to take into consideration the impact of travelling for cancer treatment on patients and caregivers, particularly when the patient is a mother.

In summary, when patients were diagnosed with recurrent cancer their needs increased and the demands of support from the family members likewise increased. The new demands involved changes of role in the family system. The data show that spouses and adult children generally filled the role of the patient, observing that when the patient was the mother of a family, the illness seemed to have a greater repercussion on the life of the whole family. Subsequent to the changes of roles, economic uncertainty could be experienced within the families as a result of reduced work hours to accompany patients and early retirements due to cancer. This new situation adversely affected the patients' and family members' emotional wellbeing. Hence, the challenge of dealing with changes after recurrence had an impact on the entire family. A recurrence affected not only the patients but also their family members. This resulted in the suffering of families.

Suffering of the families

Each of the participants of this study reacted differently to stimuli caused by a diagnosis of recurrent cancer. This work, however, aimed to find common experiences of the participants through exploring their individual reactions to the event. In constantly comparing the informants' stories, as outlined by grounded theorists, shared understandings of what cancer recurrence meant for them were identified. One of these understandings referred to suffering. In reporting the results, the concept of suffering is described and interpreted using the participants' own experiences with cancer recurrence.

As described in the literature review, suffering in this text is not limited to physical pain but comprises its psychological and social experiences. Therefore, the impact of a cancer recurrence was not simply a patient's individual experience but it was a family's experience. Suffering could occur when the physical integrity of a person was threatened, such as when the patients felt distressed or experienced pain due to side effects of treatment. It could also arise when the emotional integrity of a person was menaced, such as when the patients feared that the illness could progress. In addition, suffering was related to the perception of others' suffering. This happened, for example, when the family members suffered because their loved one was facing distressing treatment. This is what in this study is called *reciprocal suffering*. Another source of suffering for the families was *the conspiracy of silence*. These two issues are described in this section to elucidate the suffering of the families after a diagnosis of recurrent cancer.

RECIPROCAL SUFFERING

This subcategory describes the shared suffering of patients and family members as a result of recurrence. The families experienced, expressed, and communicated suffering in varying ways. Manifestations of suffering included emotional responses, such as guilt, fear, and distress. Body responses like tearful eyes were also evident in

patients and relatives when talking about their experiences of cancer. Comments from patients illustrated that there were many aspects of recurrence that caused them suffering. Like the patient, family members associated recurrence with suffering. Within the context of suffering and discomfort, however, it was the distress derived from seeing their members suffer that made recurrence more difficult to bear. As was noted by a family member, “seeing suffering without being able to do anything is the worst thing!” While family members experienced the “seeing suffering” negatively, patients associated “making suffering” in relation to the distress that resulted from their cancer condition as harmful for their loved ones. Accordingly, it was the interactive process of suffering, described here as *reciprocal suffering*, that was associated with great distress in families.

“I DON’T WANT THEM TO SUFFER FOR ME” – GUILT OF THE PATIENTS

Different signs of suffering were depicted in the interviews with patients. Some of them showed their suffering through body language, such as sighing, when I asked them to express how they felt. Others used words to articulate their suffering and frustrations. When I asked the patients who in the family was more affected by the situation of recurrence, they found it difficult to identify one person only. This difficulty also occurred with family members. This was in part because suffering was a subjective experience, so each person had her own unique approach to suffering and would express it in different ways, as a young woman reported:

Well, my parents are much more concerned than I am... That's normal, isn't it? And my husband, I realise it's hard, hard. Anyway, it's absurd to compare one situation with the other. You can't because you can't... Obviously, there are [different] ways of expressing suffering, too (Patient 6)

After a time of reflection most of the patients reported they were aware that everyone in the family was concerned by the situation. Shared descriptions of the patients showed that cancer recurrence was a family matter. The following statement illustrates the concept of the family as a sufferer very well:

Well, when this happened to me again it caused a lot of suffering. My family is suffering a lot. We've always been a very close family, a family that has always got on very well, and I see my family suffering all the time (Patient 4)

The repetition of the terms “suffering” and “family” may emphasise here the severity of the affliction that all relatives in that family were experiencing. The severity of the distress could be explained by the fact that the patient had been diagnosed with his second recurrence; meaning that it was the third time the family was confronting cancer. In addition, the patient was receiving aggressive chemotherapy that caused him to stay in hospital longer because of severe side effects. His assessment of the seriousness of the side effects and how vulnerable he felt, show the intensity of his suffering regarding recurrence of the illness.

Most of the patients referred to their spouse as the person in the family who was most strongly influenced by the event of recurrence. Sometimes the patients reported their relatives being more distressed than themselves:

My family is having a bad time. My husband is having a bad time. My family, my mother, my parents-in-law. They're having a worse time than me (Patient 9)

From the above comment, it may be difficult to explain why this female patient thought her family was struggling more than she was. However, putting her words into the context of the interview, I could interpret that this woman had found meaning to her suffering (as I shall describe in chapter 6). Though she had had cancer four times, she had a rational explanation for her situation and accepted that she might die from cancer:

The first thing you think is, “My God, what's going to happen to me, am I going to die?” But anyway, eight years have gone by, and here I am, as long as God wills, and maybe I'll die of something else and I won't die of cancer, so what! (Patient 9)

In contrast, her spouse's suffering was magnified because he could not comprehend why his wife had been suffering for so long:

Each time it gets longer and longer, especially for her. She is suffering a lot and when she seems a little better, well, back to the beginning again. And each day it's harder and harder (Spouse 9)

Cancer was seen as something that was huge and seemed never-ending, as noted by the above spouse who referred to the experience of cancer itself as a recurring experience full of suffering.

Contributing to this distressing experience was the fact that patients felt their family members were also suffering in relation to the impact of recurrence on the family. Most of the patients described their suffering in words such as guilt. Consciousness of the family members' suffering added to the patients' suffering, making the experience of recurrence worse. The following comment shows how some patients were aware of the suffering they were causing to their relatives due to illness:

I think that obviously, I have to go through this, but the others have to as well... they are suffering when they see me like this (Patient 5)

Some of them perceived themselves as a burden to their family members:

My biggest worry is that I don't want them to be worrying about me. Not that they shouldn't be concerned, but they shouldn't suffer. I don't want them to suffer for me, that's my problem. That's why, when I'm not well, I don't want them to see me, because they worry, not then. Not just because, but they have enough! (Patient 1)

For this patient, it was the perception of adding worries to their family members that made her feel bad. Similarly, most of the patients were aware that they added distress to their offspring when children were struggling to manage their own distress. Parents naturally wanted to shield their children from harm. Being unable to protect them and thinking that they were causing them suffering left the patients with feelings of failure and blame. These sentiments are captured in the following extract from a patient who was at hospital accompanied by her husband and three children:

My family is traumatised by me.

CGV: Why do you say that?

Because it's true... My family was very happy and now, they are always frightened, always watching and waiting. If they plan a trip, they have to be sure I'm all right, otherwise they call it off. Always watching if I'm well, if I'm sad, what a childhood, because the eldest is 17 now and this started 11 years ago. Then they're always concerned and I feel guilty. We want our children to be happy, not to make their lives miserable, and I have made my children's lives miserable due to my illness (Patient 2)

The above transcript shows the heavy emotions of culpability that was experienced by this woman related to the perceived burden for her children. The woman was suffering because she realised that her relatives were spending time in hospital and they were devoting constant attention to her. She was angry with herself because of what she had done to her family. The interpersonal dependency appeared not to be accepted well by the woman and this caused her great distress. Besides, she felt guilty because she had a perception of having failed to carry out her role as a mother properly. Thus, the change of the woman's self-image from being a caring mother to helplessness mother contributed to intensification of her suffering. Not only did such a sentiment result in the woman feeling guilty, her family members would themselves feel bad having to watch their loved one suffer. As noted by the daughter of the abovementioned woman:

Sometimes she says that she thinks she's in the way, that she's changing our life, and I know she feels in the way, and I don't want her to feel that (Daughter 2)

Being conscious of their relative's sentiment precipitated reactions of sadness and suffering within the others components of the family. That is, cancer recurrence was a family affair, demonstrated by a mutual state of suffering in which when a patient was distressed the rest of the family suffered. It was also the fact of seeing their ill

patient suffering that added to the distress and discomfort of family members, as described next.

“IT AFFECTS ONE JUST AS MUCH AS THE OTHER” – FAMILY MEMBERS’ SUFFERING

Any change occurring to a member of the family had an influence on the other family members. Watching and knowing the patients were experiencing physical symptoms from treatment and emotional pain due to the impact of recurrence were especially distressing for family members. Comments made by family members illustrated that they were experiencing as much or greater distress than their ill relative. The impact of cancer recurrence in family members is evident in the following statement made by a spouse with respect to the diagnosis of recurrent cancer:

When one sees a certain improvement - not one, two because there are two of us, it affects one just as much as the other (Spouse 3)

It became apparent early on in the interview with this spouse the difficult time that he was experiencing when talking about his wife’s recurrence. Data from other family members reinforced the idea that the diagnosis of recurrence could sometimes be more distressing for family members than for patients. For example, when I asked a spouse who was accompanying his wife in treatment for a third recurrent cancer about which member of the family was the most affected by the situation, he answered emphatically that he was the most distressed, even more than his wife. Similarly, nurses emphasised this idea:

Sometimes the family has a worse time with relapses than the patients themselves (Nurse 8)

When the patient has a metastasis, the family feels even worse than the patient (Nurse 13)

Specifically, it was observed that family members' suffering was largely due to the patients' lack of physical wellbeing. Realising their loved one was not able to partake in daily activities due to increased symptoms was especially difficult for the families. This may be because physical decline could represent to the families that the patient's condition could be worsening. Any sign of distress experienced by the patients made the relatives' suffering more difficult to endure.

In addition, patients' mood swings created difficult situation within the families. For example, a daughter explained how difficult it was for her to manage her mother's emotional changes. She would value knowing how to approach her mother when she was unwell. A spouse also described how much she had gone through because of her husband's changes of humour. She tried to accept her spouse's emotional reactions, such as "*this rage, this uselessness, this anger, this fury against the whole world*" (Spouse 7), arguing that ill people have to "pour their heart out" to someone and usually they do so with the closest family member.

In dealing with the patient's emotions, family members might experience a sense of helplessness. Despite the continuous attention paid to the patient, family members might see these efforts as insufficient. A profound sense of sadness would often overcome relatives when they talked about having to see their relative having to endure painful treatment and procedures. The following extract captures helplessness of a spouse:

I feel so useless because I can't do anything; just watching her suffer is the worst thing that can happen to you (Spouse 2)

It is implicit from the above quote that this family member felt vulnerable. Standing by and seeing how his relative was suffering without being able to help her, aroused feelings of helplessness in him. To reduce these feelings, the 24-year-daughter in this family sought to decrease her mother's suffering through sharing the experience of having cancer:

I often think I would prefer it was me [who had cancer], I'm younger than she is, and she has had enough or that each or us could take a little bit and remove it from her. I'm afraid of how long it is taking and how much pain she is in, and what her body looks like to her (Daughter 2)

According to this daughter, a way to relieve her mother's suffering would be through shouldering a part of the physical burden of cancer. The above quotation suggests that some relatives wished that they could have changed the course of the illness. They did not accept standing beside their relative without being able to take away the pain. They wanted to bear some weight themselves in order to lessen the amount of suffering of their sick member.

Like family members, a nurse identified helplessness in family members as causing them much hurt and suffering:

The family with the helpless feeling of what to do, how to help, what has to be done for him/her...they feel helpless, they don't know how to deal with the patient. It's hard for them as well (Nurse 5)

The physical wellness of the patients was contingent on how the relatives coped with suffering. If the patients felt physically unwell because of either the cancer or the chemotherapy, the family members reported enduring seeing their relative in pain. The next passage demonstrates how physical distress contributed to increase suffering in family members:

The days when she doesn't feel well, those days I'm worried and bad-humoured (Spouse 9)

In contrast, seeing that their ill relative was recovering contributed to the alleviation for the family members' own suffering. Sometimes, a basic expression such as a smile had meaningful impact on the rest of the relatives:

If she is laughing, simply because she has stood up and walked, and you see that she's smiling as she has gone from

here to the sitting room, or simply because she wakes up and smiles (Daughter 2)

The father of the above daughter interrupted and said:

This is our life. All the laughing, that's what she can do to make us happy, that's what we hope for every day, just that (Spouse 2)

Little signs of improvement of the patient gave a great deal of courage to the relatives. The data indicate that the families might experience suffering at some points in time, but this did not impede them finding hope to continue their way (as I will describe in chapter 6).

In summary, the family members also experienced increased suffering in relation to the patient's experience with recurrence. At times, relatives might even feel more distressed than the patient. Family members felt badly about seeing their ill relative suffer and being unable to alleviate him/her physical and emotional distress. Noting reciprocal suffering resulted in patients and family members hiding their worries and fears in an attempt to protect others from additional worries.

THE CONSPIRACY OF SILENCE

Cancer in general and recurrence in particular, carried a social stigma for most of the patients and the family members, partly because of the relation between cancer and death that generated a wall of silence for all concerned. Beyond the social cost associated with the experience of living with a recurrence of cancer, the stigma of cancer limited the opportunity for families to talk with one another openly about cancer. This conspiracy of silence contributed to isolation and suffering, also identified in other research (Byrne *et al.* 2002, Fife & Wright 2000, Reich & Mekaoui 2003). In this study, the majority of the families reacted to suffering through unexpressed worries because they thought that they lessened the family's

suffering. However, this concealment attitude caused much distress to the members of the families who sometimes felt alone and alienated in their suffering.

The conspiracy of silence involved two main reactions in the families. Such reactions are the foundation of two emerging subcategories entitled: *patients protecting family members* and *family members protecting patients*.

PATIENTS PROTECTING FAMILY MEMBERS

In order to protect those nearest to them, most of the patients tried to keep their family members out of the situation by not showing their complete feelings so as not to involve them in their own suffering. Most of the patients reported occasions when they kept feelings to themselves because they believed sharing negative feelings with their family members would not help the situation. Rather it could increase the suffering of the family:

I try not to do it [show my feelings]...because I feel that it's not beneficial, telling someone else is sharing, and then they have to worry as well. I prefer to say as little as possible (Patient 13)

Keeping silence about the illness implied a mutual protective behaviour adopted by patients and relatives seeking to create an atmosphere of normality. Many patients reported not mentioning their sentiments when they were feeling down, although they did recognise that their family knew they were going through a difficult time. Reasons for a conspiracy of silence within the family are shown next.

Some of the patients did deny the seriousness of the situation to their children because the children might not understand the situation, as they were young. This was the case of the next woman who found it complex to talk about sensitive topics with her 12-year-old child:

I don't want to mention it, I mean, cancer, the word cancer, to the eldest boy; I don't know how he would handle it (Patient 5)

Telling the truth might pose great challenges for parents because the use of language and the emotional development of children may hinder comprehension of a difficult situation, such as the cancer recurrence of one of the parents.

Some of the patients did deny the seriousness of the situation to their children because they did not want to cause them more suffering. There were situations where the patients knew that their children were suffering but they preferred to avoid sharing their emotions with children because they thought it was a way of protecting them. This is well shown by a woman who had two adolescent children:

I think that [my children] have gone through a lot because I have this personality, I'm like this, they don't let on, as they know I don't want them to suffer, then they don't show [how they feel either] (Patient 1)

Although patients wanted to protect their children by keeping silence and pretending to them that everything was under control, the children could feel that they had to keep their worries to themselves, sometimes isolating themselves and feeling more distressed. This happened with the daughter of the above patient who told me, with tears running down her face, that it was the first time she had spoken with somebody about her mother's disease, as even her best friend did not know about the situation. Keeping complete silence within the family could make her feeling isolated and not able to talk about how upset she was. The ignorance of not knowing what was going on could give rise to uncertainty, as described by the daughter below:

The fact is that no one has ever spoken clearly to my brother and me about the illness; they [her parents] sort of suggest things. But what they don't tell me, like the basics. How did it start, how she [mother] is, when will it be over, how it's going to go, you know? What hope is there? (Daughter 1)

Through the dialogue with the daughter, it became clearer that conversations about family members' worries were not happening within this family. Implicit in the words in the above extract was the wish that this daughter would appreciate knowing more about her mother's condition. When comparing the interviews between the daughter and the patient, I found that the child and the mother had different ideas about whether to discuss aspects of the illness. From the conversation with the daughter, I concluded that she would appreciate having more information to clarify her uncertainties. However, the interview with the mother showed a preference to avoid openly discussing issues of cancer with her children, to prevent them from worrying excessively. From the analysis of the dynamics of this family, I could perceive that avoiding discussing issues around cancer recurrence had not reduced the daughter's fears, but it had forced it underground. The above scenario evidences that when relatives were not told explicitly what was happening about their sick relative, they showed significant levels of anxiety. Information ambiguity about the problem resulted in emotional distress of the relatives because they might assume that things could go worse.

In addition, some patients adopted a defensive attitude by seeking not to express hostility. On occasions, keeping silence entailed lying about the reality of the situation. Some patients worried that others could not deal with disclosure of the recurrent situation. For example, a woman explained how alone she felt because she did not have the opportunity to share her concerns and preoccupations with anybody. This was partly because her parents, who were themselves going through harsh treatment because her mother had cancer, did not know about the patient's relapse. As she explained:

My mother doesn't know and when I go to see her I have to pretend, I have to look as though I'm very happy, pretend there's nothing wrong with me; but she realises that I'm lying to her, I'm no good at lying; so I'm in a mess. It's like a soap opera, and you know, that's what's affected me most (Patient 3)

The above excerpt shows how difficult it was for this patient to hide signs of suffering. Suffering that was unspoken but reflected in patients' faces appeared to contribute to great suffering. Besides, unspoken suffering did not permit the alleviation of suffering, yet it added feelings of loneliness. It can be interpreted from this quote that patients might not deal positively with their circumstance when they concealed their suffering to protect others from suffering. Minimising threat and avoidant strategy may be useful for acute points of crisis but enduring avoidance may be detrimental, also highlighted in a study of nurses' choices of management strategies in practice (Vivar 2006b). Research has indicated that avoidance typically predicts maladjustment over time (Roesch *et al.* 2005). Similarly, it occurred in patients who remained silent about their suffering. Not disclosing how they felt prevented them from using personal resources that might have minimised their suffering.

Therefore, patients used a lot of energy in protecting their loved ones from knowing how much suffering they experienced. This protective behaviour based on concealment prevented the families from sharing their struggle, resulting in increased family suffering.

FAMILY MEMBERS PROTECTING PATIENTS

In their turn, family members also protected their ill significant others by not revealing what they were feeling to them. Evidence shows that many family members were reluctant to show their emotions, as illustrated below:

Although I feel down, I don't show it because I know my mother would suffer more (Daughter 1)

I don't want to [show how I feel], how I am inside. If you tell her you're feeling bad if she's not well, she feels guilty...[because] she thinks, she says it sometimes, she thinks she's being a nuisance, that she's changing our lives (Daughter 2)

These two daughters reported hiding their feelings in an attempt to not add more suffering to their ill member. As a result, family members often played the illness down in an attempt to minimise the patient's awareness and suffering. For example, a spouse sought to keep life normal and made plans with her husband in order to let him see that things were going right. As she explained:

When I am with him I have to take him into account, make plans with him and we'll see what will happen next year, and everything I think about is in the long term...I'm not there grieving because that would be worse for him. Because somehow, if I get on with my business more or less normally, he thinks nothing has changed, and if he saw me looking bad he'd say, "I'm on my last legs, I'm dying" (Spouse 7)

These data suggest that some spouses try to protect their family member by denying reality, even though sometimes the patient and the relatives were aware of what was really happening. However, the concealment of emotions far from reducing suffering could sometimes resulted in misunderstanding within the families and sometimes feelings of indifference and abandonment by the family members. This was the case in the family of the above spouse. The patient told me having the feeling that his wife, although affected by the situation, seemed not to care less what happened to him. However, the interview with the spouse showed a contradictory scene:

I'm always there but the thing is, I need to get away because otherwise I would loose the strength I need to give him a hand... He thinks that I do as I please, it's not that what's happening to him doesn't affect me, it does, but, well, I try not to let him see how much it is affecting me (Spouse 7)

In her effort to conceal her suffering and concerns for her husband, this relative chose to confront suffering alone. Far from ignoring her spouse's condition, the woman escaped hospital temporarily to "recharge batteries" in order to be supportive of her husband. Not resolving the situation, however, contributed to the suffering of the couple. Camouflaging of feelings in the spousal interactions overshadowed the visibility of their mutual fears and preoccupations. This was found to have a great impact on the family wellbeing, as captured in the follow field note:

When I approached the patient, this latter was accompanied by his son. I then asked the patient if somebody else accompanied him apart from his child. His comment was “yes, my wife but she can’t sit still for a minute”. I felt that the patient was upset because his wife was not present. When the interview ended and I asked him when I could contact his wife, he said: “I’m sure that other patients are accompanied by their wife”. From this comment, I could infer that he was upset because he felt not supported by his spouse. However, during the interview with the spouse, I understood that the woman went out of the hospital to breathe fresh air and avoid showing her feelings to her husband when she was upset. This scenario evidenced that hiding feelings could contribute to misunderstandings, so promoting suffering within the members of the family (Field notes)

Accordingly, hiding feelings, instead of protecting family members from suffering, could lead to the patients and the relatives feeling alone in the experience of living with a recurrence. As shown in the data, the families could experience significant distress. These findings are supported by the results of a cross-sectional study about the perceived family support on psychological distress (Baider *et al.* 2003). The authors found that prostate and breast cancer couples reporting lower levels of perceived family support, experienced high psychological distress. Although the current study did not measure the degree of psychological distress of the families, their subjective experiences showed that a conspiracy of silence within the family increased signs of suffering among the patients and their family members.

Unwillingness to show their own suffering to the patients was also observed during the interviews. I observed that most of the family members expressed their anguish during interviews but they did not show their suffering when they were with the patients. Indeed, this was a fact often pointed out during the interviews with healthcare professionals. According to nurses, when significant others wanted more explanation or information about their sick relative’s condition, they frequently went out of the hospital room to ask both doctors and nurses about the prognosis and other sensitive issues that relatives did not want to share with their ill member. Besides, nurses reported that families often avoided speaking of issues of prognosis when

patients were present. That is why family members often searched for clarification and further information with doctors and nurses outside the patient's room.

Further, nurses thought that a conspiracy of suffering was harmful because it prevented the families' ventilation of feelings. Rather than sharing their concerns to alleviate suffering together, the families might talk about trivial subjects. According to nurses, the reason for this attitude was relatives thought that the patients would be emotionally worse if they knew what they had. The next extract captures the view of many nurses regarding conspiracy of silence in families:

Because they don't want to hurt the other person, because they don't want to make the patient feel guilty. Because if my husband knows I'm sad because he's ill, it's worse for him (Nurse 8)

A conspiracy of silence could even change the nurse-patient relationship because the nurses might not communicate openly with cancer patients. This happened for example when some family members asked nurses to conceal aspects of the diagnosis from the patient:

Sometimes in these cases [of recurrence], the family knows more than the patient. That is, the patient may not be told all, so you take care when you are with the patient because you don't know how much s/he knows or not (Nurse 12)

The circumstances of families' silence on some aspects of cancer might pose great complications for the nurses to deal with care. Furthermore, hiding their true condition from the patients could create the problem of managing the patients' awareness about recurrence, as emphasised by a nurse:

We don't know if they [patients] have been told everything; if you may put your foot in it, then you feel your way to see what they know and what they don't (Nurse 14)

As in the families, there were scenes during the interviews that showed that professionals did not reveal complete information to patients. A nurse went on to say:

At a medical visit, sometimes the information that the patient is given is not the whole truth. Why? Because maybe there are things [tests] that still have to be defined or because they know that the illness is having a considerable effect...and the prognosis is really bad (Nurse 9)

The above quote shows a conspiracy of silence could be observed in the hospital context. Doctors might conceal information about the prognosis of patients and nurses might collaborate in this concealment. Communication about prognosis might be difficult when there is exacerbation or progression of cancer, so clinicians might avoid information about poor prognosis. Such an attitude has been reported in studies on communication of doctors with patients with metastatic disease (Butow *et al.* 2002, Hagerty *et al.* 2005). Similarly, other studies in nursing have reported that nurses have difficulties communicating with patients about existential aspects of cancer (Booth *et al.* 1996, Kruijver *et al.* 2000). Therefore, these reports and the comments from some nurses in this study suggest an important debate about nurse-patient communication in cancer services and highlight the type of relationship of nurse-patient, particularly nurses' encounters with patients with recurrent cancer.

In summary, almost all the patients expressed that concealing their suffering from others stemmed from a need to protect their members. Family members collaborated in the concealment by not showing their real feelings to their ill relative and often to the other members of the family. The data in this study has shown that the tendency to play down the harsher realities of life with recurrent cancer could distance members and isolated them from one another after a diagnosis of recurrence, which in turn provoked suffering.

Nurse encounter with families after a diagnosis of recurrent cancer

This section aims to describe the shared experiences of nurses engaged with patients with recurrent cancer who were receiving distressing treatment. The analysis of the data revealed two recurring patterns in the descriptions of the nurses facing with recurrence. The first shows the importance of knowing the patient from previous treatment, categorised in this study as *knowing: a key element in the nurse-patient relationship*. The second represents the experiences of nurses with recurrence. This study has found that suffering was socially constructed in that nurses might feel distressed from observing the suffering of the families. Such a condition is identified here as *social suffering: the contagion of emotions*.

KNOWING: A KEY ELEMENT IN THE NURSE-PATIENT RELATIONSHIP

Knowing patients from a previous admission seemed to shape the type of relationship nurses had with cancer patients and their family members. Familiarity with patients appeared to encourage communication and facilitate caring relationships, as shown in the next passage that captures the view of most of the nurses:

If you had met them before, well they feel relieved if they come and see you because they know you and they tell you a little about how they are, don't they? But if you don't know them, well, they don't often even tell you... normally, the person you get on best with is someone you know (Nurse 1)

This extract suggests that many patients did not spontaneously disclose their emotional concerns during inpatient or outpatient stay. Familiarity with nurses seemed to affect the amount of information patients disclosed about their psychological concerns. The same appeared to happen with patients when they knew nurses from previous hospitalisations:

I don't always want to [talk], but if they've been there for some time and I know them, I'm pleased, I tell them my concerns, my fears (Patient 2)

The above extract exemplifies how knowledge of nurses was also important for patients to develop a good relationship. For this patient who had been hospitalised on several occasions in the same medical unit, knowing some of the nurses in the unit gave her confidence to talk about her feelings of fear and worry. Rapport between the patient and nurse seemed therefore important for openness of feelings and effective communication.

In addition, knowing the family appeared to have a positive influence on the way nurses managed recurrence:

If my relationship with the patient and the family member is good, it's much easier for me and for them [because] if you know them, well you know what to say to them (Nurse 13)

The above data suggest that having a previous relationship with patients might be useful in identifying families' concerns and being supportive to them.

Periodicity of cancer treatment made it possible for nurses to know the patients and their cancer trajectory:

With cancer patients, as they're there every 28 days or 20 days, well then, you follow them. In the end it gets to you, it's quite a situation, for me it's the worst, the emotional part (Nurse 5)

Caring for those who were long-term suffering seemed to involve empathy and love. It is suggested that some of the nurses felt so emotionally engaged with some patients that they deliberately participated in the family's suffering. Likewise, some nurses got involved in such a way that the wish for improvement of the patients might be reciprocal to that of the family. This was observable when a nurse explained how happy she was when a known patient was discharged from hospital.

Throughout the interviews with nurses, it was found that the way the nurses behaved appeared to be dependent on the kind of relationship that had been established between them and the families. Knowing the patient appeared useful most of the time because the closer the relationship, the better communication was. Other times, however, knowing could actually make a relationship harder, as shown below:

When it's a recurrence, to start with you already know the patient and, like it or not, you've already gone through hard times with them, and here, I don't know if it's because the nurses' station is close by, well you feel close to many patients, then it's hard, of course it's hard (Nurse 10)

It is shown above that having to get through rough times with families facing a new cancer resulted in the nurses developing a closer relationship with cancer patients and their family members. Developing a special relationship with these families might involve the nurses becoming more concerned about the suffering of the families. Indeed, nurses might become greatly distressed by the experiences of others' suffering. This is what in this study has been referred to as *contagion of emotions*, which is widely explored below.

SOCIAL SUFFERING: THE CONTAGION OF EMOTIONS

Suffering was found to be socially constructed and to present co-dependent features and one could not exist without the others. Suffering started when a patient was diagnosed with cancer and endured when the person's life was disrupted again by a recurrence of cancer, as was noted in previous sections. According to the social interaction framework, an individual exists in a world that is socially and symbolically defined (Blumer 1967). To some degree, a similar type of existence refers to social suffering (Wilkinson 2005). That is, a person suffers within a social context in which other people, most notably her immediate family, also suffer. Nurses, as social beings, also suffer when they care for others, albeit with a different

intensity and emotional response. This position is complemented by Morse's writing on her praxis theory of suffering (Morse 2001) that elucidates that:

Those observing the sufferer to some extent share the emotional response or are moved to compassion, compelled to console, commiserate, sympathise, and pity...This response in others to alleviate suffering is probably innate, although we recognise that those with certain relationships to the sufferer or those with certain roles or professional preparation have priority access to comfort the sufferer (p. 55)

By means of the social interaction approach, in this study the phenomenon of suffering was found to be constructed in the tripartite relationship between the patients, the family members, and the nurses. The next passage shows the nature of suffering of a veteran nurse encountering with known cancer patients with recurrence:

Normally, the patients who come with a recurrence, because we've been here for years so we know them from the first time; then it depends on what the person is like. It's not fear, it's often you yourself, it depends on how well you know them, so you are upset...because whenever you have to face them, you feel very distressed, don't you? (Nurse 10)

This extract depicts knowing the patient as an important aspect contributing to nurses' contagion of suffering. The nurses expressed the distressing experience of caring for patients with recurrent cancer in many different ways. Caring for these people was about healing suffering as well as sharing feelings with them. When asked, "what does a cancer recurrence mean for you", a nurse answered:

You feel disappointed, you say, "jeez". I don't know, maybe you have been dealing with patients and you see them back, for you too it's like, I don't know, it's that feeling "again". I feel it too.

CGV: And again, what does it imply?

Well, really, it means, for me as a nurse, I don't know how involved I feel, it's more them. What happens is that they pass it on to you. Then maybe you feel more involved, or I don't know, you try, really, you work in the same way if it's the first, second, or third time, I can't explain. But maybe psychologically you are more affected, more involved (Nurse 12)

Similarly, the data above illustrate how the patients' own condition could strike feelings into nurses. It was emergent from the interviews with nurses that the patients' and family members' suffering contributed to the fact that some nurses were emotionally affected, though in different ways and intensities.

Some of the nurses were concerned about becoming too emotionally involved. Therefore, some nurses consciously put some distance between themselves and their patients to protect themselves from suffering. The next quote provides an excellent description of the distancing techniques used by a nurse who had been working in cancer services for 14 years:

You try to keep your distance, not by not helping, but by not getting too involved, because they are a lot of patients, you meet a lot, and the families too, and like it or not, you feel involved and they need it too. I don't know; there are times when you feel you're interfering too much (Nurse 7)

While I was interested in the ways in which nurses understood a recurrence of cancer, I also was alert to the ways in which the apparent "sensibility" of the nurses impacted upon the quality of their relationships with the families. In this regard, the patients' personality and age was mentioned as impacting on the type of relationship between nurses and patients, as noted by a nurse:

It also depends a lot on age, on the person, because, like it or not, you don't love everyone in the same way, you can treat everyone the same, but the feeling is very personal and you can't avoid it (Nurse 10)

The personal characteristics of the patients seemed to influence whether the nurses engaged in a closer relationship with the families. This assumption suggests that the nurses might develop special relationships with some patients. In reverse, the individual characteristics of the nurses could influence the type of interpersonal relationship with families.

At the same time as the nurses responded to their commitment of caring for suffering people, they faced their own fears and suffering. On one hand, the nurses' confrontation with suffering might contribute to their distress because of a certain projection of their self onto the meaning of suffering. On the other hand, this confrontation could have a positive impact on the nurses' everyday lives, both professionally and personally. Understanding the suffering of others might be useful to find meaning in life, as described by a nurse with 29 years of experience in nursing:

For me at least, many things make me think about my life. Day after day, it makes me think it could happen to me, to someone in my family, to my kids. Then, it makes you look at life in a different way...What I mean is that it makes you take every day precisely as it comes, I don't know, making the most of every day and enjoying every moment of every little thing (Nurse 10)

This extract emphasises mutuality in the caring relationship; nurses could suffer from observing and comprehending the physical distress and emotional suffering of others. However, nurses can also be enriched through caring for individuals who suffer.

In summary, the data in this category identified as *nurse encounter with families after diagnosis of recurrent cancer* highlights the extent to which the experience of human suffering in cancer recurrence involved far more than the physical pain. Further, it seemed that when nurses felt empathy for the suffering of the families, the phenomenon of social suffering might be associated with the effort to understand the emotional needs of patients and family members during recurrence of cancer better. Finally, the data have elucidated that the nurses are both professionals who seek to

alleviate suffering just as they are persons who suffer from observing the suffering of others.

Summary

This chapter has presented the findings of this study in relation to the impact of a recurrence of cancer, as perceived by the patients and their family members as well as by the nurses who cared for them. In this context, particular attention has been paid to the understanding that fear of recurrence during survivorship was part of the experience of recurrence. In other words, the fear that cancer recurred led families to be on their guard and fearing medical follow-up because they associated it with the possibility of a relapse of the disease. However, it was when the patients were diagnosed with recurrent cancer that the fear of cancer recurring became a reality for the families. This time was experienced by the patients and their family members, and even by some nurses, as a distressing event that required the families to face the physical and psychosocial consequences of cancer again. The metaphor of “*again*” used by all the participants to describe the beginning of a new experience with cancer symbolises the meaning that families and nurses attributed to the event of cancer recurrence.

In this context, suffering was the common response to the impact of recurrence. While the literature very often proposes a view that suffering is very individual in nature, the findings from this study throw light on the fact that suffering affected interactions with the personal world. That is, suffering was experienced by the family as by the individual. In this respect, the data in this chapter show the unity of the families concerning suffering: when one family member was distressed, the rest of the family suffered with and for the patient. Moreover, the data give direct insight into how nurses experienced the recurrence of cancer of patients. Suffering took on a social dimension in that it was not just a family experience, but also it might be a social experience.

Considering recurrence was identified by families and nurses as a distressing experience, at times even more distressing than the first cancer, an understanding of the nature of suffering after cancer recurrence is provided in the next chapter which describes the emergent concept of demoralisation as a response to recurrent suffering.

CHAPTER 5

DEMORALISATION AS A RESPONSE TO THE SUFFERING OF RECURRENCE

The difference is that you never get used to this. You're always hoping it's not going to happen, whenever we leave this place, that nothing will happen, and when the axe falls, you feel the same thing all over again, I've got the same anguish, the same huge pain in my soul (Spouse 2)

Introduction

This chapter examines the shared experiences of the participants regarding a key concept which emerged from the data, labelled as *demoralisation*. The concept is often associated with depression and major mental disorder (Clarke & Kissane 2002, Kissane 2004). In this study, however, the concept has been related to an emotional response to the suffering caused by a diagnosis of recurrence. The patients' and family members' responses to recurrence were in the form of demoralisation which was characterised by *exhaustion*, *uncertainty*, and *reawakening of the fear of death* (see Figure 8). As described in the previous chapter, the patients' and their family members' responses to recurrence were interdependent; each affected the other as symbolised in Figure 8 with a two-way arrow. Furthermore, an interrelationship existed between demoralisation experienced by patients and family members and *the difficulty that the nurses encountered in caring during recurrence*.

This chapter describes the aforementioned four categories and their subcategories in an attempt to illuminate the nature of demoralisation during recurrence of cancer.

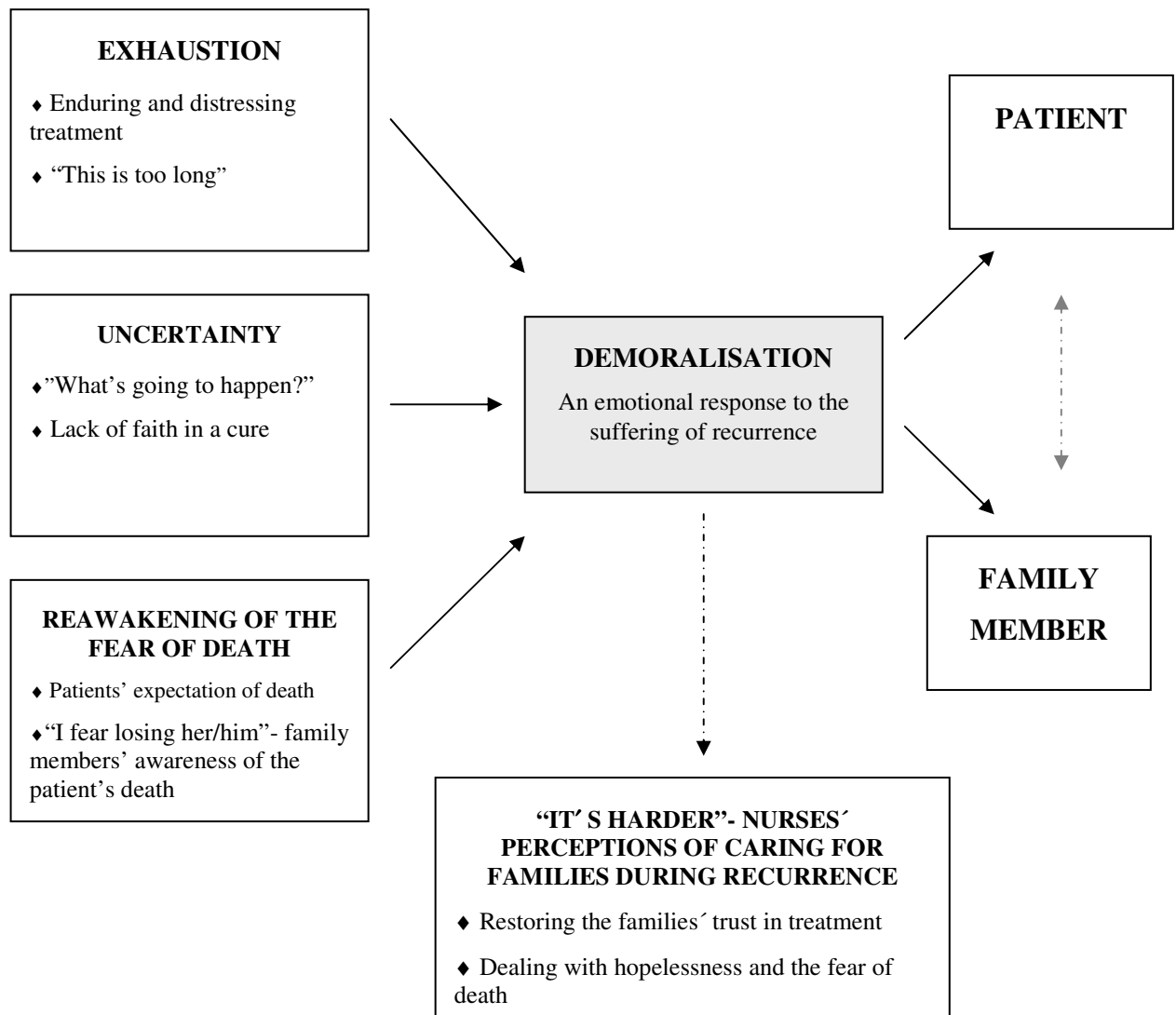


Figure 8. Families' experience of demoralisation and nurses perception of caring for families during recurrence

Exhaustion

Exhaustion designated the emotional overtiredness caused by the accumulation of earlier experiences with cancer together with the experience of recurrence. Recurrence led to periodic visits to hospital for treatment that caused physical

exhaustion. The physical fatigue owing to procedures involved psychological tiredness that, in turn, was linked to demoralisation. Demoralisation was therefore an expression of the suffering caused by a prolonged experience with cancer treatment and periodic hospitalisation.

ENDURING AND DISTRESSING TREATMENT

This category reflects how getting through new treatment for recurrent cancer contributed to the exhaustion of the families. The presence of unpleasant symptoms due to chemotherapy, such as fatigue, and the repeated time with cancer treatment had an effect on the patients' quality of life. The phenomenon of recurrence meant having moved from the experience of past treatment and hospitalisation to being once again in treatment. For those patients who were dealing with a first recurrence of cancer, it was their second experience with cancer. For others, it was their third and even fourth experience with cancer. Arriving at that point, most of the patients and family members were exhausted by the course of the illness.

Recurrence entailed experiencing the monotony and boredom of hospitalisation. In this regard, some patients felt exhausted because of frequent hospitalisation and harshness of treatment. This might contribute to the patient's suffering, as can be seen in the following:

You feel bad...physically and mentally, because now after the operation, well the operation and the first chemotherapy session I've had, these sessions they're giving me are very strong, it means three days hospitalised here (Patient 3)

Being in treatment and visiting hospital regularly was tiring, both physically and psychologically. Patients and their family members described how long their experience with cancer was. It was as if time slowed down to the extent that one year seemed an eternity. Usually, the discomfort associated with being in hospital and

feeling sick was a distressing state that might lead some patients to interpret the situation in the sense that cancer was no longer under control:

I don't see much future for me, I don't want to think, just day-to-day and I won't think. I want to go home now and then I'll come back one more time, but never again (Patient 2)

The difficulty in managing the situation accordingly resulted in the above patient believing that some sort of unresolved outcome was to be expected. Exhaustion might evolve into the idea of giving up subsequent treatment and follow-up (as I shall describe later).

In addition to experiencing frequent treatment and hospitalisation, the patients and their family members, notably the caregivers, were no longer able to carry out all of their normal day-to-day activities:

Although this [relapse] has meant a surgical operation, it has meant treatments, well, that are always troublesome, it's always, it upsets your life, you are forced to go to hospital, coming and going, having the treatment, all the bother you have because of the treatment the person is getting (Spouse 6)

As can be seen from the above quote, both the “coming and going” to hospital and the harshness of the treatment the patient was receiving contributed to making the families feel exhausted.

Chemotherapy, specifically, made the patients feel very sick, as illustrated by the following:

Well now with the treatment, well it leaves you flat, it takes away your will to live, your hair, your appetite, you've lost weight. What's more, apart from having this pathology of the tumour, I am an insulin-dependent diabetic, which makes it difficult for me to put weight back on, and my defences are low (Patient 7)

The effects of chemotherapy in combination with the consequences of recurrence, which in this case was a diabetic disease owing to a cancer of pancreas, became so severe that it made the patient feel really unwell after each session of chemotherapy. Indeed, during the chemotherapy, most of the patients reported receiving aggressive treatment that sometimes required management at hospital:

Well, at the moment I'm not having a very nice time because in the last few days I've had a terrible, terrible time. This treatment they've given me is very hard. Very, very hard (Patient 4)

Indeed, many patients reported treatment for recurrent cancer being harder than first treatment for cancer:

I think the amount of the products they're putting into my body is very different from other treatments, because, for example, last year when I had the chemo sessions with radiotherapy they were lighter and I didn't feel so bad, but this time I've felt so much nausea, I've run a temperature, I've had herpes because of the drop in defences, which really made me feel bad. Then you feel bad psychologically, you feel bad physically, you have to depend on other people to help you (Patient 3)

The varying side effects of treatment caused the patients to “feel bad”, affecting the patients’ physical and psychological wellbeing. Besides, adverse effects of treatment in some patients might be so disabling that they needed help from others. In such instances, the harshness associated with the symptoms of treatment became worse when the patients were dependent on others. Indeed, from the interviews with the patients it emerged that all of them were concerned in varying degrees about the lack of total independence. Most of the patients found the prospect of being physically dependent on their family members deeply upsetting. Others perceived they were a burden for their loved ones, particularly during treatment.

For example, some of the patients reported that their body was no longer as strong as it once was. Permanente sequelae due to previous cancer and its treatment, in addition to the symptoms caused by the current recurrent cancer, contributed to the

distress of the patients. Some patients suggested that dependence became stronger when they had a recurrence. For instance, a patient explained how mobility limitation due to bone metastases caused her great emotional discomfort:

[Changes?] Well, lots. Radical changes. That is, immobility, inability to move. Because that means being at home more...well, of course you depend more on people (Patient 6)

The above extract shows this patient's worry of losing her independence. In fact, through the interview, comments were repeated about the great importance she gave to maintaining self-sufficiency and independence. She strongly refused to be dependent on others. Feeling dependent might result in some patients being distressed.

The unpleasant feelings after chemotherapy were reinforced by the fact that therapy was frequent, as emphasised by one of the patients in his first chemotherapy session after he was diagnosed with distant lung recurrence:

Chemotherapy again and every day, every 20 days (Patient 8)

"Again" denoted for this patient a point of return to tiring treatment and treatment-related side effects. From the analysis of the data, I observed that the patients who were beginning the chemotherapy regime seemed to show higher levels of emotional tiredness compared to those patients who were completing treatment for recurrent cancer (see patients 1 and 6). This may suggest that patients with a recent diagnosis of recurrence looked back to their memories to create their present. In this case, the future in relation to end of chemotherapy might be perceived as rather distant. However, those getting to the end of treatment looked to their present experiences to create their future. In this case, the future might be perceived as a closer future, resulting in great relief.

Whether patients had started treatment or were finishing it, they all associated chemotherapy with long and distressing treatment. The impact of treatment is well

illustrated by the following description of a woman who had been treated for breast cancer recurrence three times:

At this stage you're a little tired, because it's been eight years, and you feel older and your faculties are weaker because, obviously, don't forget that they have given me cell transplantation. I was very unwell then and, obviously, I'm not that young any more... I have terrible osteoporosis...I go every month for the treatment, and clearly, my health is not as good as at the start (Patient 9)

When patients had a hard time with previous treatment, the multiple sequelae made them more sensitive to current treatment, which in turn compounded their exhaustion. It is common for cancer patients to experience physical and emotional sequelae due to their first cancer (National Cancer Institute 2002). Some of the patients explained that they had minor long-term problems from chemotherapy, whereas others such as the above patient reported permanent sequelae. The accumulation of sequelae and consequences brought about by recurrent cancer might bring loss of self-esteem in patients. Next is the response of a woman who experienced so many severe side effects as a result of treatment for recurrent cancer that she had to be hospitalised until symptoms remitted. To the question “what changes have you experienced after the diagnosis of recurrent cancer?” she said:

Well everything, I came here [hospital], they treated me and I've never got well, I've had a temperature, with a fistula, a rectum-vaginal [silence] (Patient 2)

Enduring treatment was a major issue for this woman, both at physical and psychological levels. She was no longer able to do the housework because her health had declined significantly and she was feeling frail. Going through cancer and its treatment repeatedly, seemed particularly demoralising for the woman who reported “being tired” of beginning all over again. In addition to the unpleasant symptoms, another distressing issue was physical changes as a result of the loss of parts of the body. Mutilation of one part of the body contributed to suffering of the patients, as depicted in this extract:

Apart from the cancer, they've taken out a lot of things, they've taken away my bladder, I have a bag for the bladder, they've really messed me up, they've taken a kidney as well, so I see myself like a freak, a useless thing, that's rotten, that's how I feel (Patient 2)

This extract shows the intense emotions that the woman experienced in relation to her physical appearance. Having gone through all these physical changes resulted in the woman's loss of self-esteem and subsequent suffering. Not only did physical symptoms result in the patients feeling exhausted and distressed, family members were themselves distressed at having to watch their loved one suffer so much. The next quotes show the daughter and spouse of the abovementioned patient also experienced feeling exhaustion and great distress in response to seeing their relative's suffering:

I'm afraid of seeing how long this is for her, and that she aches all over, and she has a colostomy (Daughter 2)

Her father interrupted:

... she was a very good-looking woman, not because she is my wife, but she was very good-looking, well, seeing all these things, [referring to the colostomy and mastectomy], it's very hard (Spouse 2)

Seeing that the physical condition of their loved one was deteriorating because of repeated surgery and chemotherapy made the experience of recurrence more stressful in the family. The impact of the physical losses experienced by the patient was referred to by the spouse as "it's very hard". The longer the "very hard" experience was, the more difficult the experience was for patients and families.

A very distressing aspect for patients, notably for those with young children, was not being able to take care of their children because they felt generally unwell. For example, a woman who had a 13-month baby reported great frustration caused by breast cancer-related consequences. She could not care for her child as she wished because of limited mobility in her arm due to lymphoedema:

A complete change because, of course, I'm very restricted. Restricted because I can't pick up the kid, I look all right but it's limiting. Then you feel really useless (Patient 5)

Another woman reported feeling guilty because she could not look after her 10-year-old child because of the fatigue:

Well, I can't look after the kid the way I'd like to, because you don't feel like it, you feel awful, and all that has an effect on you. It has a terrible effect on you (Patient 3)

This patient reported no longer being the person she was once as minimal activity implied more of an effort for her. The woman was being treated with high doses of chemotherapy that caused a great impact on her immune system. As a result, she showed feelings of tiredness and lack of energy that prevented her from caring for her 10-year-old as she would like to. This contributed to the guilt of the woman who reported finding the situation overwhelming. These findings are consistent with other research that has found that cancer-related fatigue is common among patients who have received chemotherapy, and it has important negative physical and psychological consequences (Curt *et al.* 2000). Certainly, experiencing fatigue and other limiting symptoms resulted in some patients in the current study feeling powerlessness and guilt, as noted above.

Likewise, a nurse highlighted the significance of which member of the family was ill in relation to the impact on the family:

I notice a difference between men and women [laughs] and the family, well it's different if there are children... Then again, if the children are 18 or 20, they feel more protected, but if they have small children, they feel bad, they have a hard time. Hard mostly because they feel powerless (Nurse 5)

For most of the patients and family members, although chemotherapy was necessary to fight cancer, it was associated with negative effects in the body, which in turn led to suffering in the patients and their family members. A daughter emphasised this as follows:

I've always thought that chemotherapy sounded bad, it's a solution for the illness, but on the other hand, what it cures inside, it takes away from outside (Daughter 1)

A patient emphasised the idea of enduring, harsh treatment using the following metaphor:

I say that I'm like an apple: on the outside, I'm perfect, but I'm rotten inside (Patient 5)

In summary, the recurrence itself and the changes associated with having to face new treatment resulted in the patients and the family members being physically and emotionally affected. The cycle of going through treatment, remission, and recurrence was exhausting for the families because of physical changes, but also, because of the uncertainty about when this would finish. The next section puts emphasis on the long trajectory of cancer that made the experience of recurrence more demoralising.

“THIS IS TOO LONG”: A NEVER-ENDING SUFFERING

Components of lasting suffering were identified with prolonged experience of cancer. “*This is too long*” was an expression often used by the participants to describe suffering through the cancer trajectory. The following captures the view of many patients and family members in relation to the cancer trajectory:

I suffer because this is too long (Patient 1)

Therefore, I considered it relevant to use the expression as a main category because it illustrates the long-term experience of cancer as perceived by the respondents perfectly. Having been diagnosed with cancer in the past, being diagnosed with cancer in the present, and anticipating a possible relapse of the illness in the future caused suffering to the families. The experience of cancer was revealed as an extended period in the families' lives that became accentuated after a relapse.

Recurrence was more than cancer. The process of repetition made the experience unique. The memories of the experience of cancer allowed a present experience of recurrence to be created. Memories of first tumour and periodic check-ups after treatment completion seemed to contribute to the meaning of recurrence as a continuation of past crises. When cancer returned, the families remembered the time when they were diagnosed with the first cancer. That is, a cancer recurrence meant falling back and returning to the past. This contemplation of memories and the present distress reinforced the perception of the families about recurrence as associated with enduring suffering.

In this way, to relive past suffering and to deal with present suffering characterised the experience of recurrence as a long path that never ended and contributed to the suffering of the families:

I know this is going to go on a long time, a very long time, and I'm afraid of suffering myself, rather than myself, making my family suffer. That does worry me. That, my suffering, well I suffer, but it's relative because I can see it's going to be a very long time (Patient 1)

The patient's perception of suffering in the present that would continue into the future represented the significance of cancer as never-ending suffering. That is, past suffering was extended into the present to develop present suffering, which took the form of expected suffering in the future. In addition, it was also the cumulative events over time that caused the families feelings of ongoing suffering that shaped the meanings of cancer recurrence as a too-long experience. This is well illustrated in the response of the spouse of a woman who had had cancer four times. When asked about the most difficult aspect to deal with, he replied:

The suffering that never finishes (Spouse 9)

A spouse whose wife had been diagnosed with cancer eleven years ago and since then, she had had cancer two more times, expressed the idea of enduring and intense suffering as follows:

It's come back; it's the illness that never ends. A distressed person always thinking about the same thing, it's never-ending. It finishes you off your life, but it never ends... You die before of fear or sadness (Spouse 2)

The above quote shows that what became most distressing in this spouse's experience was his experience of enduring suffering. His suffering appeared to be a consequence of his perception of the long trajectory during which he had been struggling with cancer and he had experienced a lot of uncertainty. From this excerpt, it is also deduced that living with cancer was associated with endless suffering. It appears that there was no point marking the end of cancer. In this regard, a recurrence of cancer symbolised the articulation of suffering from the past to the present. Recurrence was represented as the ceaseless flowing of suffering due to the coming and going of cancer that seemed never-ending. Moreover, living with cancer and experiencing its exacerbations revived the experience of suffering and made it more difficult for families. As explained by a family member of a patient being treated for a third cancer:

Each time it's longer, especially for her. She's suffering a lot and when it seems she's getting a little better, well it starts all over again, and it's harder every day...It will be eight years now and it's a long time (Spouse 9)

Recalling family members' accounts of the continuity of suffering in cancer recurrence, some patients differentiated cancer from other diseases to highlight the notion of duration. For example, a woman expressed the continuing nature of cancer by describing her thoughts when she saw at hospital an adolescent who had lost his leg:

A car accident would have taken my leg but perhaps the illness would have ended. But with cancer, you don't know if it's ever going to end or not (Patient 1)

According to that woman, the experience of living with cancer was different from that of having an accident. Although in both cases the person might suffer a

mutilation, having an accident caused temporary suffering. However, living with cancer entailed the threat of the possibility of recurrence that families feared so much. Similarly, another patient compared suffering in cancer with suffering in cardiac disease:

Someone with heart trouble is operated on, they stick in something, and she doesn't have to suffer like we [cancer patients] do (Patient 7)

Like this patient, a family member talked about the chronic nature of cancer in relation to death:

The difference there is between dying of a heart attack and dying of cancer, well apparently, the difference is that with a heart attack you don't realise (Spouse 10)

Although death resulting from a heart attack would be difficult for family members, cancer-related death was even more distressing as the patients experienced enduring suffering as opposed to a quick death from a heart attack. From the above quotes made by patients and family members, it can be inferred that in the cancer trajectory, the families experienced lasting suffering that resulted in emotional exhaustion. Accordingly, a spouse perceived death from cancer as a slow process that caused great suffering. The following quote shows how the spouse experienced the distressing death of his brother due to cancer:

You're looking at him and it's all suffering. However, there are people who have a problem, they have a heart attack and they don't leave them to suffer, but the thing is how this person [cancer patient] can suffer so much. It's terrifying that you could see that this person is dying like this (Spouse 2)

This extract seems to suggest how the previous experience of his brother's death was projected onto the current experience of his spouse's condition. In this regard, the husband experienced great suffering because of the anticipation of the possibility of his wife's death (as was indeed observed through the interview). It is suggested that

the families' past experiences with the death of a family member were part of the participants' present experiences. The more difficult the previous experience with death was, the greater the suffering appeared (the issue of death is discussed in detail later in this chapter).

Likewise, nurses indicated the long-term nature of cancer that led to continuing threat in the families. For example, a nurse explained the fear of families in relation to the enduring experience of cancer as follows:

What they are afraid of is that, well, "the disease did begin with a new treatment but it's come back", then I think the fear they have is, OK, "now I have to go through all this again and it's terrible, but will it happen to me again? Will it never finish? Will I always be under treatment?" (Nurse 7)

In the description of the battle against cancer, time acquired important significance, both for families and nurses. Continuity in suffering was shown by its "presentness" after a diagnosis of recurrent cancer.

In brief, the factors involved in "*this is too long*" were an accumulation of previous experiences with cancer, and treatment that were combined with periodic follow-up during remission and survival. Other disturbing events, such as the feeling of long-term suffering, added to the accumulation of negative experiences resulting in the families feeling exhaustion. In this regard, recurrence appeared to denote a continuation of past suffering that did not seem to have a predictable end. Therefore, recurrence was conceptualised as an event that evoked memories from the past that gave suffering a unique significance in the present. Further, suffering in cancer recurrence was not experienced in a "punctuated" manner. Rather, the present suffering, while distinguished from the past and the future, was experienced as connected to the past and the future. It was this contemplation of the continuity of suffering due to recurrence that shaped the concept of exhaustion. Ultimately, the patients and the family members found it emotionally exhausting to have to once again get through all the harsh times and the harshness of the cancer-treatment experiences. This "exhaustion" feeling, when combined with uncertainty, only led to

more feelings of fear that might be very demoralising for the families, as we will now see.

Uncertainty

Treatment for recurrent cancer was time of uncertainty because the families observed their present from the perspective of the past. In other words, the patients and family members drew their conclusion about the future from what they had experienced in the past. In this regard, dealing with recurrent cancer seemed to cause an enormous amount of uncertainty. The families felt they had less control over fighting the cancer as recurrence emphasised the feelings of uncertainty. The uncertainty was caused by fear that the treatment would not work and by the unpredictability of the disease.

“WHAT’S GOING TO HAPPEN?”

Most of the families felt the need to live “day-by-day and minute-by-minute” because of the uncertainty about what could happen in the short-term. This was the case for the spouse of a patient with recurrent pancreatic cancer:

You learn to live day-by-day and minute-by-minute because you haven’t got much more than the next few days. Well, waiting to see how it goes, and always the same question, “What’s going to happen? What’s going to happen? What’s going to happen?” I think that once a person has had cancer, you feel you’re always waiting to see what’s going to happen (Spouse 7)

Living with a recurrence of cancer seemed to result in an insecure life situation. All the patients and relatives interviewed expressed a sense of frustration and struggled to cope with the unpredictability about the future. The next extract referring to cancer as an unpredictable disease captures the view of many nurses:

[This disease] is very treacherous because you think you are well, and without noticing, there is the patient back again. Then you feel as if the disease has let you down, that you feel well, controlled, checked by your doctor, having colonoscopies and suddenly, “ah” it’s back. That’s how I describe it, a treacherous disease (Nurse 11)

Therefore, the harshness of all the uncertainty resulted in increased suffering for the patients just as it did for their relatives. This included such tough times as fearing that while the patient might look better, something bad could happen. In agreement with cancer taken as unpredictable, a nurse provided an account that reflected many nurses’ view of cancer as full of uncertainty:

For me as a nurse a relapse proves to me that, well, we still have cancer, there is nothing certain about it, even with a good prognosis that you’re given, as it makes you see there is nothing certain and that in the end [cancer] is there (Nurse 10)

Likewise, most of the patients in this study identified their future as uncertain. This perception of uncertainty meant lack of plans for the future. In this regard, the patients did not program any long-term activities because they were unsure whether they could carry them out. Having a recurrence appeared to contribute to life being put on hold and the families being stuck in the present. Consequently, the patients and their relatives sought to live the present and did not make important plans for the future. Some families lived the present so intensively that their lives sometimes became confused. The following illustrates this:

I say I can’t see a future, but obviously, you are living so much in the present that you feel out of place (Spouse 10)

The view of cancer as an unpredictable illness also made for uncertainties and fears among the family. The daughter of a woman diagnosed with a second recurrence reported:

Well, the way it’s developed in my mother, you can see more or less, she seems to be getting better, but you never know,

because if in May she finished the treatment and now she's back, your doubts come back, your qualms: When will it end? How will it end? (Daughter 1)

Similarly, nurses identified the uncertainty experienced not only by the patients but also by their family members:

I think that the family members are like the patient, that is, they feel the same stress. Then, it's fear, fear of what is going to happen too, fear of how (Nurse 6)

Cancer can be so unpredictable that it may greatly affect families' lives. This was the case for a spouse who reported the following:

You can't make plans, you don't know what's going to happen, and then you can't make an appointment with the painters because you don't know what's going to happen. That's just a graphic example of how you live, I mean it's a restricted life, very, very restricted, and you live for the disease, that's our case (Spouse 10)

For this spouse, it seemed as if cancer marked the dynamics of the family. It should be noted, however, that this was not the case for the rest of the families. Although families did not make long-term plans, recurrence did not stop them from living the present when the patients felt better. This was observed when I asked a patient in treatment for a first recurrent pancreatic cancer about his plan when the treatment was over. The patient said:

Well. Go on working and enjoying life...until it [cancer] comes back again.

CGV: Do you think it's going to come back?

I don't know but it's said that these things come in threes. It could (Patient 7)

Although patients and family members felt uncertain about what could happen, they tried to live the present as much as possible (as I shall describe in chapter 6). However, the uncertainty was always present in the families' lives, to the extent that the above patient expected a second recurrence after the end of the current treatment. As can be seen from the descriptions of the participants in this section, the nature of the cancer and the condition of the patients helped to mark the families' degree of uncertainty. While the unpredictability of the progression of cancer added to an understanding that cancer was a "treacherous disease", a recurrence only reinforced the uncertainty about the future, so patients thought they would not get better.

LACK OF FAITH IN A CURE

The category entitled *lack of faith in a cure* describes the feelings of some patients and family members in relation to their awareness of the effectiveness of treatment and feelings of lack of faith. Seeing that cancer had recurred and that previous treatment had not been successful might bring up the question of whether or not treatment for recurrent cancer would be effective. Understandably, the fact that the previous treatment was ineffective influenced how the patients saw the current treatment for recurrent cancer. If previous treatment did not work, as the cancer had come back, why would the treatment work now? This uncertainty affected how some of the families lived:

[Always] with uncertainty, you don't know, it's because cancer is a very treacherous disease, it goes wherever it likes (Spouse7)

In this regard, the approaching end of treatment created a paradox of happiness accompanied by long-lasting uncertainty. Patients and their relatives were happy to finish treatment but at the same time, they remained aware of the inherent unpredictability of cancer, including the uncertain outcome of treatment. For example, one patient described her fear as follows:

Fears? Well, that the chemo won't work and I won't see my daughter grow up (Patient 15)

The patient was very fearful about what could happen if treatment was not effective. Her words show that what she most feared was that treatment would not work, so her disease could advance resulting in death. She was frightened for herself but much more frightened for her child. It must be noted that this woman, although unsure about her prognosis, reported being hopeful about the effectiveness of treatment. Whereas most of the patients tried to maintain hope after a recurrence (as I will evidence by describing the concept of *persevering to live* in chapter 6), some of them were more negative and they did not express the same hope in relation to recurrence:

The first time I was much more optimistic than this time, I thought I was going to get over it the first time. I mean, I was sure I would get better, now I'm not sure, not at all sure (Patient 3)

The woman recalled the time when she felt optimistic about treatment and about a possible cure. Indeed, the period of greatest optimism was the time of primary diagnosis. However, finding out that ovarian cancer had recurred was a “terrible blow”. This meant her prognosis, which might have been good, was no longer nearly as hopeful. The words of the woman suggest that she might assume that her recurrence signified the possibility of death. The spouse of the woman, in a separate interview, corroborated such significance by saying that his wife was always asking doctors how much time she had left. It should be mentioned that the woman had a regional ovarian recurrence; which is a type of cancer often perceived by women as having a poor prognosis (Bowes *et al.* 2002, Howell *et al.* 2003, Sodergren 2003). In addition, her mother had also been diagnosed with ovarian cancer and had to be hospitalised frequently because of the progression of cancer. Seeing her mother ill and a constant reminder of the possibility of death strengthened the woman’s anxieties, resulting in increased pessimism about the future.

Understandably, thinking that treatment might not be successful caused great distress to patients and family members. This is how a nurse from one of the oncology day unit described the feelings of the families after getting the bad news:

They are afraid, they're afraid that "If it's come back, now what? Will the treatment work? Will it do anything for me? What's going to happen?" Then, they are afraid it won't be effective (Nurse 6)

These questions were combined with feelings of fear, deep grief, and even despair for a time. Nurses perceived patients being more negative after recurrence than the first time they were diagnosed with cancer:

When they get the first diagnosis and the first treatment, I don't know, they tell you they have a great chance [to survive] and as they have great faith and hope that everything will go well, and everything does go well, and they seem to have finished up the treatment and they're home. And then, they relapse and it all starts all over again, yes I know, they have experience that it [treatment] works, but I also feel that they don't have as much spirit or hope as the first time, and also physically they are more tired; it's logical. I myself think that [a relapse] must be much harder (Nurse 7)

Nurses assumed that a recurrence was related to "being harder" because of hopelessness. The next extract made by a nurse has the intention to highlight the attitude of patients to the first cancer:

It's not the same the first time, they [patients] have more hope of getting better and they're going to have chemo, but, well, there's no time limit, a few months and they'll be better and go home, I don't know, [newly diagnosed patients have] more hope (Nurse 12)

Although nurses and patients highlighted hopelessness after recurrence, especially when some of the patients felt treatment might not be effective, all continued their treatment calendar. This is in fact reasonable because all the patients in this study were receiving active therapy to treat their recurrent cancer.

An important observation was that the experiences about hope in treatment differed between the patients and relatives. This loss of hope in treatment was in fact expressed more by the patients than the interviewed family members. Some patients might express their loss of hope in recovery, and thought the worst. However, the family members' description of hope was more positive. The next conversation with a woman with a second recurrence evidences the above observation:

They [family members] think that the day will come when I will be well, everything will go back to normal.

CGV: And what do you think?

Me? That every day it's further away, every day: I feel different from two years ago. Two years ago I thought everything would turn out like it did 10 years ago, things would happen, but later it would be better, it would all work out. Now I feel that is just a follow-up (Patient 1)

For a patient with a second recurrence, hope seemed to be lost because treatment was not longer effective, and he felt a deep imperative to be with his children:

I simply presume there is nothing can be done and then with the children, and that, and nothing, but I have no plans for the future (Patient 10)

In a similar view, some patients associated cancer with palliative care. This was the case for a patient who explained how doctors had given up hope of her recovering six years ago after she was diagnosed with her first recurrent cancer. She continued describing the incurable nature of cancer as follows:

Radiotherapy and chemotherapy are palliative; everything is palliative in cancer, now everything is palliative. Survival is greater, but it's not a cure. Some day it may be chronic, but for now, it's palliative (Patient 6)

The woman seemed to suggest that having cancer did not only bring to mind thoughts of lack of faith in a cure but it also entailed to come progressively closer to death, referring it as palliative illness.

A woman diagnosed with a second recurrence expressed her hopelessness and exhaustion through negative thoughts. When asked about her thoughts after she knew cancer had come back, she responded:

*I can't tell you, you feel like dying, [you think about]
committing suicide [silence] mostly you don't want to go on
(Family 2, patient)*

This reaction was attributed to the fact that it was the third time that the patient had cancer, losing slowly faith in recovery. In addition, the woman was experiencing severe symptoms due to the chemotherapy that obliged her to be at hospital. She said that the stress of the medical procedures together with the harshness of treatment was too great, and this situation made her think of withdrawing from follow-up after completion of the current treatment. Furthermore, the fact that her family had abandoned their daily activities to be at hospital with her made the experience more distressing. All of these stressors were also related to her enduring experience. She said she had the feeling of being under constant treatment that made her physically unwell and emotionally exhausted.

The interview with this patient showed that the woman was experiencing high levels of distress, which were associated with her physical decline and long-lasting stay in the hospital, feelings of guilt for her family (as described in chapter 4), and the fears surrounding the possibility of death. Although the woman's family supported her, she reported being treated with antidepressants because she was depressed. Indeed, I did notice during the interview that the woman was expressionless and had no interest in continuing follow-up visits, as her words above show. Although I did not have access to her psychiatric records, I can relate these symptoms back to the scientific literature on psychological disorders. Depression is a psychiatric disorder that often results in loss of pleasure and lack of interest and expression (American

Psychiatric Association 1994). Hopelessness, guilt, and suicidal ideation may also be present in depressed people (American Psychiatric Association 1994) and in cancer patients with depression (Breitbart *et al.* 2000, Massie *et al.* 1994). On several occasions, the abovementioned woman expressed that she felt she was a burden to her family and guilty of the suffering of her family. As mentioned in chapter 4 when talking about reciprocal suffering, this situation caused the woman great suffering. These observations find confirmation in scientific literature. Studies have identified that factors, such as hopelessness and the perception of being a burden to themselves and to others contribute to great emotional suffering among cancer patients (Rydahl-Hansen 2005), and may even precipitate thoughts of suicide (Filiberti *et al.* 2001, Kissane *et al.* 2004). However, it should be noted that the above woman was the only patient in the study mentioning thoughts of suicide. The remainder of patients manifested their will to continue fighting despite exhaustion and the fear of what might lie ahead.

However, the recognition of recurrence and that the whole process of cancer would have to be lived through again and again was demoralising for many of the participants. This was how a nurse described the feelings of families having to deal with future relapses of the illness:

They come the second time, they are already thinking about a third, a fourth time, and that they will never leave. It seems to me that they feel everything is blacker (Nurse 11)

According to this nurse, patients found recurrence “harder”, especially when it was related to the expectation that cancer would recur again. In this regard, the patients and the family members feared about what could happen if treatment did not work and the disease progressed.

The reports the participants made about dealing with the uncertainty of recurrent cancer highlight the dreadful fear the families experienced during this time. Not knowing if treatment would be effective in bringing about a complete or at least a partial remission, the families re-lived the possibility of an imminent death.

Reawakening of the fear of death

This category describes how participants, including patients, family members, and nurses shared the view of a cancer recurrence associated with the possibility of death. Although the general concept of death was similar for the participants, there were differing views according to who described the condition. The different perspectives, including patients', family members' and nurses' concerns in relation to death are explored in this section.

The diagnosis of recurrent cancer precipitated feelings of uncertainty because for many, recurrence was synonymous with death. The view of cancer recurrence as a life-threatening event was socially constructed. The association of cancer and death did not appear merely among cancer patients. In this study, the family members and the nurses similarly associated the two-term concept with words such as death, mortality, and fatality:

[Cancer] is such a strange illness, always related to death, too, when we speak of cancer we are speaking of death, and some people get better and some don't, it's an illness like any other, but the difference is that nobody dies of the flu or chicken pox (Spouse 3)

The above extract shows that cancer is still a disease that brings thought of death, also evidenced in other research (Clarke & Everest 2006, Flanagan & Holmes 2000). During remission of the illness, when there was no sign of evidence of cancer, and patients felt better because of the absence or lessening of physical symptoms, most of the families stopped thinking about the possibility of imminent death. However, when the families were informed of disconcerting news in a follow-up visit, they woke up to the sound of the alarm. For many, recurrence suggested the idea of death limiting life again. In other words, the awareness of death came before recurrence; it first emerged when patients were diagnosed with primary cancer. However, the repeated diagnoses and successive treatments for cancer reawakened the fear of death, and both patients and family members became demoralised.

PATIENTS' EXPECTATIONS OF DEATH

The concept of “death expectations” was presented by Glaser and Strauss in their work *Time for Dying* (1968). The authors identified four types of “death expectations” that explained temporal aspects of the “dying trajectory”. These involve: (1) certain death at a known time; (2) certain death at an unknown time; (3) uncertain death but a known time when certainty will be established; and (4) uncertain death at an unknown time. It is considered important to refer to Glaser and Strauss’ study about the “dying process” because, during the interviews in this study, it became apparent that thinking about the possibility of one’s death contributed to different “death expectations”. In this section, the patients’ descriptions of their awareness of the possibility of death are discussed.

Patients expressed their awareness of the possibility of death in different ways. For example, a woman manifested her awareness by describing her dreams in relation to death expectation:

Death was me coming, they[family members] were coming up and, well, I knew I was going to die and that it was time for me to die. But I was walking perfectly well like them, they were going up, and as I can't go up, well, I was waiting, and they asked me: "Ready?", and I said, "Not yet", [I'm not dead]. Then there was a light like a coffin and they came and I said no, I haven't died yet, and they threw away the coffin because I hadn't died. Or something like that. I don't know if that is death... Death is not in any bed or anywhere, it's walking and waiting and saying I'm dying, like saying I'm ill, it's looking at my health. It's taking away [my health], but I'm not dead yet (Patient 1)

The relation between death and time is highlighted by the woman’s description of death as related to a developing process rather than a quick event. This extract also shows that the “dying trajectory” has duration, shape, and implicit expectations concerning the interrelation of time and uncertainty. These findings suggest that recurrence was related to an enduring awareness in which death was uncertain but recurrence might accelerate the possibility of death.

Most of the patients in this study did articulate the words “death” and “dying” and they used words related to the process of dying. This reflects that the patients related recurrence to the possibility of death. However, the participants generally expressed their concerns about death when they trusted me, generally towards the middle or end of the interviews. In spite of the difficulty of talking about one’s death, some patients sought to explain their perceptions with situations that they experienced in their daily lives. For example, when asked about his main fears, a patient eluded the question but affirmed that fear was omnipresent in his life. He explained how difficult it was to get to sleep when he thought of problems that could never be solved. In order to unmask what I had deduced from his words (“that fear of death was his main problem because death was inevitable”), I sought to clarify if what I had interpreted from the patients’ words was what he really had meant. Therefore, I asked him about his plans when he finished treatment. He replied:

*Well, let me tell you: I’d rather be cremated than buried
[laughs] (Patient 10)*

Through the interpretation of these words and the following conversation with the patient, it became clearer that what he was referring to was the awareness of death. In line with Glaser and Strauss’ findings, it can be said that this patient viewed a certain death but at an unknown time.

Fear was the term most frequently used to characterise the expectation of death after a recurrence of cancer. For example, fear of pain was a way of expressing awareness of death. This was the case for a woman who referred to “the fear of pain” as her main preoccupation. In order to explore whether there was a relationship between *fear of pain* and *being in pain*, I asked her whether she was in pain while I was interviewing her. She responded:

*No, but I don’t know, it’s like almost [silence] I’m afraid of
physical pain, I’d prefer to die of a heart attack than be in
pain (Patient 2)*

This participant expressed the stressor of death as a threat to her physical integrity. The woman was overwhelmed because she did not know whether her condition was part of recuperation or a sign of further degeneration. Based on the interpretation of the words “it’s like almost” and on the patient’s subdued voice when she answered the question, it seemed that the woman accepted death. That is, the woman kept the terror of imminent death at the forefront of her mind, yet she did not know when this would occur. In such understanding, the quicker she died and the less she and her family suffered the better. When reporting their emotions about the difficult time that they were enduring, family members also highlighted the relationship between long-term suffering and dying from cancer (as I shall present in the next section).

Other patients referred to the expectation of death in terms of fear about what it would be like at the end of life. This is illustrated in the next responses:

I’m afraid of suffering. Suffering pain, anguish, I mean, maybe, the final phase (Patient 5)

The only thing that frightens me, you know, is that I might not realise when it’s the end, that I won’t grasp what’s happening (Patient 11)

Patients especially experienced expectation of death when they considered the possibility that the cancer might become out of control and they would be unable to manage the situation. An alternative description of the fear of death was articulated through visualising death and its rituals:

I often think that if I die, what really frightens me about death is being put in a coffin because I have claustrophobia (Patient 1)

For this patient, thinking about death was frightening because she feared being confined in a small space. She claimed to have an intense phobia that overwhelmed her. However, what is surprising from this quote is that the woman was talking about her worries after death. The interpretation from this description is that the patient was

really expressing her fear of dying, although she tried to maintain constant tranquillity about it when she was with her family.

Knowing that one could face death at a young age was highly distressing. The next extract is from a young woman on anticancer therapy for a loco-regional ovarian recurrence who expressed her fear by saying that she was still too young to die:

I am 45, and you don't think you are going to go so soon, do you? [Almost in tears], you always feel that, not wanting to be an old woman who can't look after myself, but you don't think you're going to receive a blow as hard as this, do you?
(Patient 3)

In addition to being concerned about their own death, some of the patients were more concerned about how their family would cope. During the interviews with patients, it became apparent that thinking about one's death when the children were small was one of the most difficult situations in the patients' lives. Indeed, the above woman was concerned about what would happen to her 10-year-old son if she died. Her constant worry about his son and the fear of death made her feel particularly vulnerable. Likewise, all the patients spoke about their fears of dying and concern for their loved ones, especially for their children:

I can see the boy is affected, he cries, the girl doesn't, she's always concerned about me, but she doesn't cry. The eldest doesn't want to leave me alone at all, and my husband is scared... Scared of what's happening; that I may die (Patient 2)

As shown above, for many patients abandoning their family and particularly their young children was their main preoccupation. This might be due to the fact that most of the patients interviewed were in their forties and had young and adolescent children they had to protect and care for, as discussed in chapter 4.

The fear of death was even more central to patients when they felt unwell due to chemotherapy. It was during the times that physical discomfort was great that the patients might interpret such times as signs of imminent death:

I believe in the saying that we are born and we die, but the later the better, but the truth is that even if you don't want to, you think about it, particularly when you're not well (Patient 1)

Similar to the above woman, her daughter associated severe side effects of treatment with the possibility of the death of her mother. She explained, in tears, how she feared for her mother's life when she had to have an emergency hospitalisation.

It was different when we had to hospitalise her with pericarditis. I had a terrible time; it looked as if we're losing her, that's what I fear most. That's it: that he could slip away. I couldn't stand it. I really couldn't (Daughter 1)

Therefore, the experience of severe symptoms reawakened the awareness of death and caused the patients and family members experienced emotional suffering.

An alternative view of the possibility of death was the loss of fear of death, manifested by some patients. For example, one woman explained the loss of fear with the argument that she knew death because she had once been very close to it. The woman, whose first recurrent cancer had been diagnosed six years before her second relapse, had been so critical than doctors had given up hope of her recovering. As she explained:

I've seen death close up, very, very close. I mean, I've seen death face-to-face (Patient 6)

Having previously encountered death "face-to-face", was certainly shocking and devastating. However, the woman felt she had overcome the fatal outcome and she explained to me how this encounter had given her great strength to continue the battle of cancer and to enjoy life.

For other patients, religion protected them against fear of death (as I shall explain in chapter 6). Another orientation consisted of avoiding thoughts about the possibility of death. This can be illustrated by a patient who had experienced the death of two of his four brothers due to cancer:

I try to forget what's happening and that's it, you do as you can and that's it, nothing more, I don't think about it, thinking makes it worse (Patient 8)

Distancing himself from the expectation of death was beneficial for the above patient because it appeared to reduce his suffering. This is understandable because memories of the loss of close family members may make the patient feel more vulnerable to greater distress. However, it was difficult to know if the patient's attitude of avoidance relieved him of suffering or made him suffer in silence.

While some patients accepted death as a possibility, others seemed to be constantly remembering the finiteness of life, and so were highly distressed:

Your life changes completely because you're concerned that, you know: you don't know when you're going to die, no-one knows that, but when you're like this, it's like a sentence, I mean that's that. And it's hard, very hard...I more eager about everything, with more, as if I'm not going to make it (Patient 11)

Although several patients expressed their knowledge that they had to die one day, as everybody does, the feeling of being finite emerged after a diagnosis of cancer and it was exacerbated after the recurrence of the illness. At this point, limitation was more clearly presented even though patients did not know when death would arrive. In keeping with Glaser and Strauss' theory of the dying trajectory (1968), it is suggested that some patients in this study identified recurrence as related to "a certain death but at an unknown time" whereas others identified recurrence as related to "an uncertain death". It is further suggested that the patients' understanding of recurrence influenced their "expectations of death". Therefore, the type of expectation of the patients increased their suffering. In this regard, the more the patients expected a certain death at an unknown time, the more they suffered. Likewise, the more the patients feared a forthcoming death, the more demoralised they were.

“I FEAR LOSING HER/HIM” – FAMILY MEMBERS’ AWARENESS OF THE PATIENT’S DEATH

The term *awareness* was first used in Glaser and Strauss’ work on patients dying in American hospitals (Glaser & Strauss 1965). The theory is concerned with the transfer of information from medical and nursing staff to terminally ill patients. Glaser and Strauss’ analyses on the interactions between hospital staff and dying patients led them to identify four contexts of awareness. These are: (1) “closed awareness” in which information about prognosis and terminality is concealed from patients; “suspected awareness” in which patients suspect but are not told; “mutual pretence” in which both patients and professionals know but collude in agreeing not to discuss the matter; and “open awareness” in which both sides are aware of the probability dying. It should be remembered that the patients in this study were not terminally ill. Besides, this study did not focus on exploring the situation of awareness in Spanish hospitals, although some data on this matter are presented in this section. While the awareness context theory is not appropriate in this work, it seemed relevant to refer to it to introduce this section. This is because, not surprisingly, this study found that like the patients and the nurses, the family members associated recurrence with the possibility of future death. Such an association provided insights into the relatives’ responses to recurrence and the nurses’ attitudes towards families facing a recurrence of cancer.

What emerged most frequently in the interviews with the relatives was fear and anxiety regarding the loss of the patient. The idea of the possibility of death and the pain of physical separation contributed to suffering in relatives. Like the patients, family members vividly described how the fear of death began at the time that their relative was first diagnosed with cancer:

To tell you the truth, if you had asked me what I was afraid of at first, I would say it was when I came down off my cloud and realised that death and life really do exist. I knew that people died and I had been to lots of funerals and in fact, I had lost some loved ones, but I wasn’t conscious of what death was. Death for me has always been like a natural

process that one has to go through, but I only really realised what death means when he became ill and was operated on, and I felt that he was going to leave me and go away (Spouse 7)

Often a profound sense of sadness would overcome relatives when they talked about being aware that their relative might die. They described this experience as being the worst. This was the case for a daughter who reported with tears running down her face:

[Death] is the only thing I can't bear but anyway, you never know and you see it as a possibility, but I think I couldn't (Daughter 1)

The “you never know” emphasises her overwhelming fear about the possibility of her mother’s death. Even though her mother might be stable, the daughter anticipated feelings that the disease might be progressing. The thoughts of the possibility of death contributed to the daughter’s fear, which in turn provoked her feelings of suffering. As I tried to understand the suffering of the daughter better in relation to the meaning she attributed to recurrence, I noticed that the fear of her mother’s death was so intense that she preferred not to talk about it.

Another daughter expressed the fear of the possibility of her mother’s death as follows:

It scares me, but the truth is that, I don't know if it's better or worse, but I won't accept that my mother may die. I don't want to think about it (Daughter 2)

The idea of losing a loved one resulted in great distress for the family members. In fact, many of them recalled how difficult it would be for them to live without their loved one. Perhaps even more telling was the fear of death expressed by many family members in relation to the possibility of death. When family members were asked about their fears, many responded:

Fear, fear, fear of losing her, fear of that, three or four different fears at the same time (Spouse 2)

Fear of losing my father, it's a great fear, isn't it? It's the worst I have (Son 7)

I'm afraid of losing her. That's my fear (Spouse 9)

These examples demonstrate that the immediate concern of relatives after a recurrent cancer was fear of death. It is important to emphasise that most of the family members avoided the use of either the noun *death* or the verb *to die*. In their place, they utilised the verb “to lose”. The use of this verb appears to mark a human-oriented connotation. Death might not simply mean a time of life cessation in which the result was a physical death but it acquired a more humanistic meaning. To lose might convey here a value to the individual being. The uniqueness of the person, meaning the *mother*, the *father*, or the *spouse* was more important than her physical loss.

Some relatives did avoid speaking about the death of their ill family member despite the fact they behaved in a way that showed they were afraid of its possibility. However, others expressed their anxiety when they were asked about how they felt. The wife of a patient with distant lung cancer stated:

How do you think I feel? Scared, [silence] about what's going to happen to him. Still, I'd like him to live longer. The children feel the same; they're convinced he's going to get better. I'm scared about the future, of what might happen [silence] (Spouse 4)

Interestingly, male family members were more reluctant to express the possibility of the death of their ill relative. This might be due to the fact that I was a female and I was younger than the interviewed male. This is a position that can be understood in our social context, in which men are generally seen as less communicative regarding their emotions and feelings. However, as the interviews went further, they felt more

confident and they revealed some of their intimate worries to me. The next piece shows a husband's concerns about the possibility of his wife dying from cancer:

[Cancer] is a problem you can get better from, or not so well, or not at all. Shortly after we came here we all thought about the three options, and we always come to the worst one. That she won't come out of it (Spouse 3)

The above quote clearly shows how the spouse associated cancer with the possibility of death. Another spouse described the fatal nature of cancer as follows:

Nowadays there are things to ease the pain but she is dying little by little (Spouse 2)

This spouse referred to dying from cancer as a process based on physical and psychological pain. Although physical pain might be alleviated, the emotional suffering was intense and constant. For this spouse, as well as for other family members, the pain resulting from enduring suffering was the most difficult to bear.

Although all the family members feared the death of their loved one, most of them were hoping that the patient would live many years:

Well, worrying about whether she will get better, let her get better, at least if possible let her survive a few more years at least (Brother 5)

The brother wished that his sister could live long enough for her children, the youngest 13 months old at the time of her diagnosis of recurrent breast cancer and the oldest 12 years old, to reach older age. In wishing his sister could survive longer, the brother's words reflect the presence of a heightened sense of mortality. However, the hope that things would be better and that tomorrow would be brighter shows a search for meaning within the experience of recurrence and perseverance despite adversity (as I shall explain in chapter 6).

Similar to the patients and the family members, the nurses viewed cancer as evoking thoughts of death:

[Cancer] is like a sentence; you introduce yourself to someone who, sooner or later, won't be with you, with her family (Nurse 10)

The above quote, made by an experienced nurse, captures the view of many nurses in relation to cancer as associated with death. Further, all the nurses identified a cancer recurrence as a reinforcement of the possibility of death.

Although family members feared the death of their ill relative, they tended to hide their fear. This observation seems to indicate a cultural approach toward death. The fact that the family members thought about the potential death of their relative but all of them kept their fear secret may be attributed to the difficulty of the families in confronting the subject of death. This is in line with other studies showing how difficult it is for societies to handle death (Kastenbaum & Costa 1977, O'Gorman 1998, Palgi & Abramovitch 1984). Like families, nurses found it difficult to confront death, as is evident in the next quote made by a nurse with 2 years experience in cancer care when she referred to death among cancer patients:

Many of them [relatives] ask you, "What will it be like in three or four year's time?" And you're saying to yourself; "My God! What nonsense. Undoubtedly, they've only another nine months and they'll be getting worse all the time" (Nurse 11)

The above quote depicts a scenario in which the nurse prevents the family members from knowing the truth about the patient's cancer trajectory. Although nurses might confront death every day in their practice, they found the emotional aspect of dying to be one of the greatest challenges in cancer care.

In summary, the recognition of recurrence as bringing probable death overwhelmed the families. To varying extents, the families responded to a potentially fatal ending by showing feelings of fear and distress. The harshness of the new treatment and the psychological distress they had to endure caused demoralisation. This type of distress characterised by feelings of exhaustion, uncertainty, and fear, seemed to vary depending on the type and number of recurrences the patients experienced, the

duration and aggressiveness of the treatment, and the negative meaning attached to recurrence. Although the families experienced demoralisation as a response to the suffering of recurrence, they did their best to continue the battle against cancer, as did the nurses who cared for them. However, the very nature of recurrence resulted in all the nurses considering caring for these families to be difficult. Next is the view of the nurses in relation to caring for individuals when facing a recurrence of cancer.

“It’s harder” – nurses perceptions of caring for families during recurrence

All of the nurses interviewed felt that caring for patients with recurrent cancer and their families was extremely challenging, despite having to manage this situation on a regular basis. The complexity of approaching patients with a recurrence of cancer was consistent among all the interviews with the nurses. This was expressed using sentences such as “it’s hard”, “it’s harder”, and “it’s difficult”. It should be mentioned that the complexity of the caring process was related to the emotional management of cancer rather than to the physical and treatment managements of the disease.

The category of “it’s harder” describes the nurses’ perceptions of the difference between caring for patients with a first diagnosis and patients with a recurrent cancer. The data revealed shared factors in cancer nursing that might make the nurse-patient relationship complicated. Some of the factors mentioned were gender, age, and personality. Several nurses, for example, explained their difficulty in communicating with male patients. According to them, this was because men were generally less open to discussing intimate concerns with nurses. In contrast, women were more expressive and more open to sharing their concerns. Besides, various young nurses reported being more comfortable with relatives whose age was similar to that of their own. With regard to personality aspects, some nurses reported that there were people with whom they did have aspects in common, as it could occur in every day life. It

has been also shown that “knowing” the families from a previous occasion could complicate the nurse-patient relationship because of the contagion of emotions (refer to chapter 4). In addition to the abovementioned factors, there were others factors, specific to the recurrent phase of cancer, which made the experience of caring for patients with recurrent cancer difficult.

Nurses found it hard to deal with the loss of patients’ hope in treatment and the exhaustion of the families, the unpredictability of the disease and the uncertainty, and the fear of the possibility of death. Such situations, identified in this work as demoralisation, placed great demands on nurses, requiring them to undertake emotional care to manage the emotional suffering of the families when facing a recurrence of cancer. The next section gives details on the nurses’ experiences of caring for this cancer population. Two main categories were identified that explained the reasons why the nurses found caring “harder” in the recurrent phase of cancer. *These were: restoring patients’ trust in treatment, and dealing with lack of hope and fear of death.*

RESTORING PATIENTS’ TRUST IN TREATMENT

Despite the best efforts to remove a malignant tumour, the reality was that cancer recurred. As described earlier in this chapter, this situation contributed to making the families, especially the patients, lose their hope in treatment. This situation, in turn, contributed to the nurses finding it difficult to deal with the patients, especially because the patients were overwhelmed. One nurse referred to questions about treatments that the patients often asked:

Will this treatment work for me. Why didn’t the previous one? Will I have another recurrence? What if I can’t get over this? (Nurse 8)

Although these questions were difficult to answer, if not impossible, the nurses found it crucial that the patients should develop new trust in treatment in order to accept

that the right treatment decision was being made. However, this was challenging because many patients “did not believe in the chemo”:

They don't believe in the chemo, because when they had it before they were told it was to avoid it. Well, when they have it, what happens? That they no longer believe [in the treatment] (Nurse 13)

Helping patients with recurrence was even more difficult than at initial diagnosis since the patients knew that the treatment with the most hope of success had failed:

That mistrust they have in the medication because the first or second line of treatment hasn't worked...and I see they are worried at the beginning because [they say], “Will this medication do anything for me if the previous one didn't do anything?” (Nurse 3)

Such mistrust made it difficult to build up confidence in the treatment for recurrent cancer. Patient with recurrence were much more likely to report a negative reaction to initiating chemotherapy treatment than newly diagnosed patients. In addition, helping a patient with recurrence was difficult because communication was limited:

In a recurrence the patient is more reserved, quieter, more tired, you feel very sorry for them. For me it means, it's harder to go in, because it's more difficult. You feel worse because they know all about the previous process, the treatment, then a recurrence is worse, it's harder for us to face to them and for them to face us, it's harder. It's harder, much harder (Nurse 5)

The above extract shows that developing confidence and approaching a patient who had relapsed was a great challenge for this nurse, just as it was for all the nurses. This might be due to the fact that recurrent patients felt more pessimistic about their prognosis, and questioned whether any treatment would help them. The difficulty of working with patients with recurrence also revolved around the nurses' challenge in dealing with existential issues of the families, as presented next.

DEALING WITH LACK OF HOPE AND FEAR OF DEATH

Caring for people dealing with a recurrence was a great effort for nurses. The attitude of the patients toward the illness was a factor that made the development of a healing approach during a cancer recurrence extremely challenging. According to the nurses, patients with a relapse were not as optimistic as in a first diagnosis:

With a recurrence, they [patients] don't believe it's going to end in the same way. [They see] they can have it again, and then they're like more watchful, more sceptical in the recurrence than if it's a first time (Nurse 14)

The above nurse used the word “sceptical” to refer to the poor possibility of recovery from cancer. According to her, the difference between newly diagnosed patients and recurrent patients generally related to the variation of optimism about cure. This scepticism created a challenge for nurses in supporting the patients, as shown next:

The moment a patient with a recurrence comes is difficult. Difficult because they don't expect to have to go through all that again and the prospects are worse, and they feel so terribly uncertain. Well, it's hard to bear because of their state of mind; they need much more support than the first time (Nurse 6)

Another nurse reiterated this view by comparing the state of mind of newly diagnosed patients and recurrent patients:

There are cases when a primary tumour appears and well, they are very depressed and feel terrible and that, but usually they appear and well, it's a different mentality, more ready to fight, “Well, I'm going to get over this”. It's different. But obviously, being with a patient who already had a recurrence, it's like I said before, it's harder, they fight once, now it's the second time, they depend on will power to get through (Nurse 12)

The above quote shows implicitly that the nurse found it harder to care in recurrence because patients were often disheartened due to the uncertainty of the future. Another nurse emphasised this idea as follows:

With the disease (silence), it's hard work because there is no way to cheer them up, I mean, even if they don't show how discouraged they are (Nurse 3)

Some nurses described patients with recurrence as reserved and quiet individuals. For example, a nurse with 28 years of professional experience and 6 years as a cancer nurse found it difficult to communicate with patients with recurrent cancer because they were generally despondent and less communicative:

In the recurrence, the patient doesn't have such a positive attitude to get over it, to fight, they feel worse. Then the effort to communicate with them is greater, to try to talk, to try to overcome it, whatever, or the side effects... Then it's harder because it's more difficult to give advice, to encourage them (Nurse 5)

Some nurses compared the relationship between patients with first cancer and patients who relapsed in order to stress the difficulty inherent in the recurrent phase:

You always talk to the newly diagnosed patient, I don't know, with more confidence (Nurse 10)

It's easier to deal with people the first time they come (Nurse 11)

The above extracts have been used because they show that caring for first cancer patients was perceived to be easier compared with caring for recurrent patients. This is a strategy mentioned by the pioneers of grounded theory as helping to enhance the rigour of the results (Glaser and Strauss 1967). The fact that the nurses felt more comfortable when caring for patients with first cancer might be explained because they might be more prepared to give information and physical care, yet they felt defenceless when dealing with emotional demands. For example, a nurse felt lost

because she did not know how to deal with some aspects related to death and the future:

When you are told they're very ill, and you know they're in a terrible state, that's it, and you don't know if they tell you they're going to die, then there are times when you don't know what to say, you feel so, it's so direct, What can you answer? How do you console a person like that? (Nurse 1)

The above extracts highlight the fact that patients facing a recurrence were generally more reticent and pessimist. In such situations, having time available was essential to create an atmosphere in which patients felt comfortable enough to disclose their concerns, especially their awareness about the possibility of death. Besides, time was necessary for nurses to identify patients' fears and to reassure them. The next extract captures the view of many nurses about the importance of adequate time to support patients:

You need time to be with a patient who has a recurrence; you need time to be with them. You need time because it's difficult, because you have to calm them down (Nurse 6)

A genuine concern was to have enough time to be with the patients and listen to them. This is consistent with studies in which the authors have identified that a lack of time is a significant contribution to poor nurse-family communication (Davis *et al.* 2003). However, time was often limited, resulting in the nurses having difficulties in addressing patients' preoccupations.

More importantly, the nurses found it hard to talk about the existential concerns of the patients, as illustrated in the next extract made by a nurse with 20 years of nursing experience:

There are moments when those people always start to talk about the disease, where they are, if they think they are going to die, if they are afraid of dying, well you talk about a series of things that are very difficult, either to say or to hear someone talking about them (Nurse 10)

Similarly, a nurse with five years experience emphasised the idea of the challenge of dealing with the patients' fear of death:

Then it's more difficult for me to deal with them because you talk the subject [the possibility of death] over more, you talk without the cancer taboos you had on the first visit (Nurse 11)

There were times when nurses did not know what to say. That situation might entail a feeling of helplessness, resulting in some nurses feeling distress. The next conversation presents the sincere feelings of a nurse when faced with a patient with a recurrence of cancer:

I feel I won't have words of encouragement or any words to offer the patient in that situation. The ideal thing is you ask: "How are you?" but it's such an open question, "Well, I feel very well because I'm not in pain", but the patient hardly ever says, "I'm discouraged". They may say: "I'm happy because I've had good news", but they will never say when asked how they are: "Well, imagine, I have very bad news ", they don't tell you. If you insist a little, "And your frame of mind?" Sometimes it's difficult to connect with the patient, that's the first thing. Sometimes you don't have time to ask them, because you know you can't be waiting, and there are times when you haven't the strength to ask: "How do you feel emotionally?"...Because I'm afraid, that's the question I often don't ask (Nurse 3)

It is evident from the above extract that communication with patients with recurrent cancer was complex. The patients did not demand extensive information about the physical effects of chemotherapy, as they already knew this well from their previous cancer. In this case, communication involved more than information; it involved more support and emotional care. However, dealing with emotional concerns might be extremely distressing. The above nurse recognised her struggle to talk about death and dying openly, and this had prompted her to distance herself from some patients. Similarly, some nurses reported using distancing tactics when they had to face a specific patient. These results are in concordance with the literature on death, which evidences that nurses find it difficult to answer questions and confront the emotions

of the dying patients and those of the family members, resulting in feelings of anxiety, guilt and helplessness in nurses (Rittman *et al.* 1997).

For recurrent patients a relapse often meant that recovery was uncertain (as shown early in this chapter). The extent of not knowing what to say might posed difficulties to nurses who might need to use specific supportive techniques, which often they lacked. In spite of the difficulties met, nurses did their best to care for their patients:

We nurses try to give all the emotional support we can [in spite of] our lack of training (Nurse 6)

I think we do give [emotional support]. Now whether I do it well, I don't know, I don't know if it is support, I can encourage them, listen, but, well, organised support, I don't know how it's done (Nurse 7)

A range of factors combined to influence the perceptions of nurses about caring for patients with recurrent cancer as being one of the most difficult in their practice. This time was difficult because the stage of recurrence was marked by swings between hope and fear of the treatment not working, a sense of hopelessness, and the revival of the fear of death. It was a time of “demoralisation”. The nurses perceived patients to be in need of emotional support; yet, this aspect of caring was found particularly tough for most of the nurses who identified care was “harder”. Although caring was relatively challenging, the nurses did the best they could.

Summary

The impact of a recurrence of cancer was a stressful event not only for patients but also for the family members sharing the experience. Likewise, the nurses perceived recurrence as causing thoughts of uncertainty about the effectiveness of treatment and the liminality of the patients' lives. Such a response to recurrence posed a great challenge to the nurses who described caring for these patients in terms of harshness

or difficulty. The participants' reports, interpreted on a more abstract level, have contributed to the development of the concept of demoralisation. Although the description of the concept is broken down into separate categories, in reality they did not exist as distinct entities but instead were interrelated and connected. The patients and family members' response to recurrent cancer affected how the families understood the phenomenon of recurrence. Their view of recurrence as an exhaustive experience, full of uncertainty and threats, to some degree determined how they responded to recurring suffering.

Demoralisation was found to be an emotional reaction to cancer recurrence. The endurance of the experience of cancer, the uncertainty of the condition, and the revival of the threat of death resulted in the families feeling demoralised. In this study, demoralisation was found to be a normal response to a life-threatening event that recurred. Normality, of course, depended on the severity and intensity of the demoralised response. For patients and families who were experiencing recurrence, "rebuilding morale" helped them regain strength to continue the battle against cancer.

CHAPTER 6

REBUILDING MORALE IN THE EXPERIENCE OF RECURRENCE

They feel discouraged at the beginning because they say “Look, I’m again with chemotherapy, or I feel even worse now, as the previous treatment was unsuccessful” but then they get morale again (Nurse 3)

Introduction

All the patients and family members, whatever their situation, expressed their difficulties in dealing with recurrence. For many, recurrence was more distressing and demoralising than the shock of the first diagnosis of cancer. Demoralisation, as a response to the suffering of recurrence, was central in the process of adaptation to recurrence. For each of these patients and family members, this was the beginning of an ongoing adaptation process, which included a search for meaning in the experience of recurrence, as well as an attempt to deal with recurrent cancer. In varying ways, the families dealt with demoralisation and rebuilt morale to adapt to recurrence. Adaptation has been described in this work as including interactions or strategies that helped the families understand the experience of recurrence and continue their battle against cancer.

The process of *rebuilding morale*, which describes the approaches of the families towards regaining control over the recurrence and life in general, took many forms. The first category entitled *the family as a resource* describes the extent to which patients and family members influenced each other to overcome recurrence. The

second category *persevering to live* captures the personal characteristics, beliefs, and abilities that resided within the individual that helped to regain control over the situation. The third category entitled *the human side of nursing care* describes how human support from nurses might be useful in maintaining some degree of “morale” to find meaning in cancer recurrence. The last category called *towards boosting families’ morale after a recurrence* is representative of how nurses responded to the concerns of patients and family members in an attempt to help them find meaning in the experience of recurrence and adapt to the new situation. All in all, the psychosocial process of *rebuilding morale* integrates the abovementioned four approaches (see Figure below).

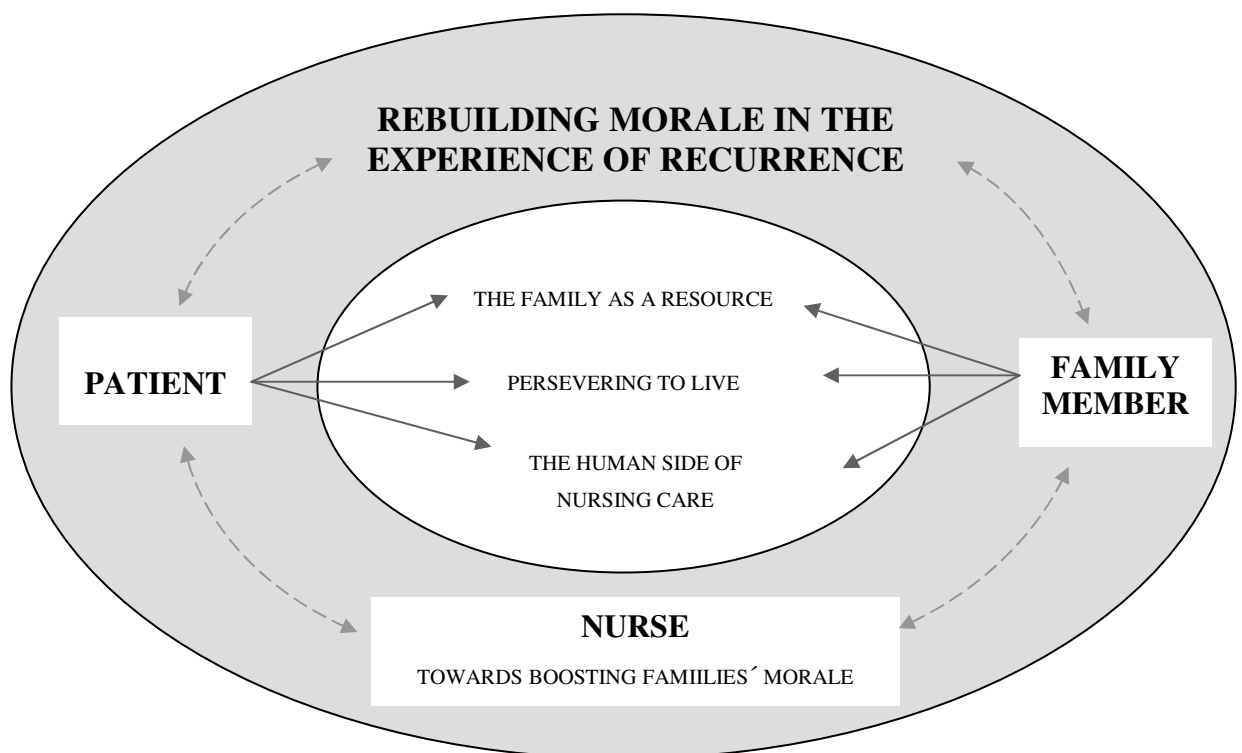


Figure 9. Family and nurses approaches toward rebuilding morale

The family as a resource

In chapter 4, we have seen how the family might be a source of potential suffering. Each member's own approaches to recurrence influenced the other's suffering indirectly. The conspiracy of silence, including the concealment of feelings from others, accounted for great suffering in the family. Besides, a high level of family support might expose the patients to the problem of guilt. However, the family as a unit also had positive effects. Overall, the interpretation of the data indicates that the family was associated with positive outcomes, and it appeared to be one of the most important resources to deal with the recurrence and life in general. This section attempts to show this by describing the two subcategories namely *family reciprocity* and *living the present in full*.

FAMILY RECIPROCITY

As families forgot the shock of having cancer again and moved through demoralisation, they all spoke about the significance of the family as a basic unit that helped them rebuild morale. This category describes the mutual influence that patients and family members had on each other's adaptation. Such relationship has been identified as family reciprocity in this study.

Both the patients and their relatives shared the importance of the family members' reciprocity as a stimulus to raising morale after a diagnosis of recurrent cancer. In the awareness of others' suffering, there was a great potential for rebuilding morale. As the spouse of a patient said:

We are all with her, the entire family here, in the room, all spending 24 hours for her. The five bring her life; it is what brings life to her...no doctors or anything. I think it is this way, if we do not come and the four of us aren't here, my wife does not get up [from bed] (Spouse 2)

I should remind readers that this family was from a different region from that of the hospital. At the time of the interview, the patient had been in hospital for nearly a month. Initially, the spouse and the children had taken turns to accompany the patient because they either worked or studied. However, they all moved to the hospital to stay with the patient when they realised that their relative needed them. This meant they stopped their activities temporarily to be with the patient. The above quote shows that the presence of the family was basic to alleviate the great suffering of the patient. Further, it is suggested that keeping the family together was significant for the patient and the relatives as it helped to get through the recurrence experience. It seemed that a close relationship between the patients and their family members might contribute the strength needed to deal with recurrence. This example upholds the evidence that perceived support of cancer families is associated with psychological wellbeing (Baider *et al.* 2003). The authors found that the couples reporting greater perceived support had less psychological distress and fewer adjustment problems.

Additionally, support from family and close friends was reported to be a great help for many patients. The next extracts illustrate the view of various patients regarding the positive effect of being supported by significant others:

[I have a lot of support] from my husband. The truth is that I am receiving support from everybody, at work, I'm surprised because I realise that I'm surrounded by many people; and they are helping me a lot (Patient 15)

The disease has helped me to find out that all the people round me, family, and work, give me [support]; it's not something I've discovered, I have verified it (Patient 14)

The patients recognised the importance of relationships with close others such as spouses, children, parents, and friends. The data show that an intimate confidant was attributable to feelings of increased self-esteem. Overall, the patients found it positive to feel valued by their family and friends. Support gave them a greater understanding of the meaning of love and made suffering more bearable. According

to nurses, family support appeared to be beneficial in facing recurrence and cancer challenges in general.

On other hand, fulfilling social roles was found to be important in rebuilding morale. Specifically, the experience of parenthood was observed to be central for some of the patients:

The second time this happened to me, [my son] was fifteen months. At that time, I always say this was a very important part of my life, because with a fifteen-month baby I had to do it for him, to bring him up (Patient 1)

This extract highlights this woman's high degree of responsibility for her child. Such a responsibility had had a positive effect on readjustment to cancer. The woman's response further emphasises the natural role of mothers regarding protection of their children. Another woman, who had a 12-year-old son and a 13-month-old baby at the time she was diagnosed with metastasis, showed great courage in continuing her battle with cancer so as to take care of her children:

And I say I have to fight for my children, and get energy from where's nothing. Try to get energy from somewhere (Patient 5)

Being a mother or father was a great stimulus for fighting against cancer for the patients with young children. The ability to become strong for the children seemed to occur instinctively when the patients had young children who needed to be cared for. At this point, virtues such as courage and vitality emerged:

The girl, only five years old, I would not like to leave her, and besides, I cannot leave her, because I want to see her getting married and having children (Patient 15)

Again, this extract shows that having young children empowered patients, in particular mothers, to deal with the challenges of recurrence. In addition, the wish to reach future milestones seemed to promote patients' optimism about the future.

It was interesting to note that the patients who reported their children as a motivation for persevering were female. This may be explained by the fact that the interviewed patients having young children were all women except one who had a 15-year-old son. In this last case, it was the patient's wife who explained that she had to fight for her family to get through the difficult time:

Both of us cannot be ill at the same time, one of us has to feel good in order to move things forward, for our son, for work
(Spouse 7)

The above data suggest that having children had a positive impact for persevering, especially for mothers with young children. This finding is in agreement with a phenomenological study about the experience of motherhood of breast cancer women with dependent children (Billhult & Segesten 2003). The authors found two main strategies used by mothers to deal with cancer: "gaining strength and support" and "turn into positive" (Billhult & Segesten 2003). To be a mother with cancer and have dependent children "implied using the strength of motherhood to balance conflicting forces, and thereby continue everyday life" (p. 122).

Overall, the data show that there was a reciprocal relationship between family dynamics and strength to rebuild morale. Patients who had family members with whom they exchanged support showed strength in regaining mastery over the recurrence. Likewise, most of families in this study gave and received great family support that helped them deal with the difficult time. Therefore, it is suggested that the family function seemed to have a strong influence on the families' attitude toward cancer. It is worth mentioning that in Spain, in contrast to Anglo-Saxon countries, there are few available support groups and associations that help to deal and live with cancer (Reuben 2004a). A reason postulated for this is that Spanish families have strong traditions of the family as a source of love, care, and support. As a result, families may have less need to find other sources of support that meet their emotional needs compared to families in other cultures. However, this is just a personal assumption that needs further examination because families change within and across generations.

LIVING THE PRESENT IN FULL

The recognition of new threat appeared to help families to move on into a more authentic mode of living. In that sense, resurgence of the fear of death (explained in chapter 5) was part of the sense of temporality and how families incorporated death into their sense of living. Most of the patients talked of their increased appreciation of the ordinary things of life such as family and friends:

Well, I'm going to tell you that it's been a period of time of eight happy years, perfect, without any concern until now. I enjoyed my friends and family (Patient 4)

After a recurrence of cancer, time was considered precious and became a value to be expended to the best benefit. Having the perception that time might be scarce led most families to change their thinking about time. The awareness of death seemed make the family realise the significance of the present and led them to appreciate each day and spend their time with their loved ones:

One thing that I have realised through life, in the course of this problem is, the intensity that we are living, both of us (Spouse 2)

When couples had a close relationship, they reached out for one another, experiencing an intimacy deepened by the course of cancer. This finding is consistent with a quantitative study that found that 42% of the 282 couples interviewed about their experience with breast cancer reported that the disease brought them closer (Dorval *et al.* 2005).

Most of the families expressed their different approaches to life. Living the present in full was important to avoid loss of time. Families did not want to waste time in case they could not enjoy the time to come. Therefore, the families took any opportunity to enjoy little aspects of life, such as being together, that might not have been taken so much into consideration before. This is well illustrated in the extract below from a

spouse who said how much he changed his view of life after his wife, who had survived 8 years, had a first recurrence:

We are all the time, without stop, action, "Where are we going this weekend?" Or "I've got a two hour break, get dressed and let's go". We normally do it since the second time. We spend less time with the children (Spouse 2)

For the above spouse living day-by-day, and even hour-by-hour seemed to be part of the close relationship with his wife. The mutual recognition that time might be limited contributed to the couple maintaining a meaningful relationship and making the most of the present. It is suggested that the ways that the couple thought about time and used it was probably due to their understanding of recurrence as related to the possibility of death. The couple's new perspective of life was accepted pleasantly by their children who associated their parents' behaviour with a better state of mind for their mother.

Fully living the present had also the meaning of differentiating between what was essential and what was less important in life. A man whose wife had had a second recurrent cancer expressed his desire not to work anymore and to spend his time with the patient. The decision of living life with his wife intensively provided him with a sense of empowerment that moved him from darkness and confusion to relief and direction. The same feelings seemed to be shared by the patient when she was asked about her plans after treatment:

Ah, enjoy life as much as I can, because my children are grown up and well, my husband has just retired, as I say, enjoy it as much as I can (Patient 9)

This "new life perspective" was general among almost all the patients and family members. Overall, the attitude of living the present in full was like a source of light that helped most of the families to move on and persevere through demoralisation. The data highlight the link between facing recurrence and using time efficiently. Both patients and family members faced the possibility of lack of time due to

thoughts of death, suggesting that the individuals' perception of the lack of time tended to be conducive to enjoying life as much as possible.

Lastly, it is important to remark that having older children at home often meant the parents had more time to enjoy each other. Among the couples with older children, they seemed to get great moral support from their marital relationship. The couples with younger children seemed to get a larger proportion of their strength from their children. Whatever the situation, the family was an important source, if not the most important, in rebuilding morale when adapting to recurrence.

Persevering to live

But, in the end, your only choice is to accept it and fight for it, because there's nothing else. You cannot choose, you have to live; you have to fight (Spouse 6)

This category refers to the patients' and families' descriptions of persevering to confront long-term suffering and the perceptions of nurses about families' perseverance in recurrence. The concept of *persevering to live* assumed an important place in the social construction of the meaning of cancer recurrence as perseverance helped when dealing with distressing events, such as a recurrence of cancer. The relationship between the present and the past became constructive in that it allowed perseverance to emerge. Being perseverant helped the families overcome temporal demoralisation and rebuild morale despite the hard times.

This main category is divided into three subcategories, namely *vacillating between hope and demoralisation*, *spirituality*, and *suffering, growth, and cancer: learning from the past and dealing with the present*.

VACILLATING BETWEEN DEMORALISATION AND HOPE

This category describes the dynamics of hope and how the families intertwined between demoralisation and hope when persevering. The use of the word *vacillating* has been chosen intentionally to highlight movement within the process.

It was compelling to observe that many patients in the same phase of cancer and experiencing similar symptoms showed different emotional reactions. For instance, some patients showed lack of hope in their words while they also had some optimism and hope for the future:

Day x was a dark day [when I was diagnosed with recurrence]; I cried for hours non-stop. I used to say: "I'm never going to get out of this, as it was a prompt reproduction, it must be very aggressive" but the day after, I woke up and I said to myself "come on! I need to move forward" (Patient 15)

Despite the darkness of the experience of having a recurrent cancer short time after the first cancer, this 46-year-old woman had rebuilt morale by persevering despite the bad news of recurrence. The change of attitude made her more willing to have courage to confront early recurrence. It seemed that with the awareness of the possibility of death, she gained strength to face the future. Later in the interview, she explained that although she had an understanding of the fact that many people died from cancer, she avoided seeing cancer as a terminal disease but she preferred to perceive it as a temporal problem such as influenza. The deaths of others close to this woman made her aware that her own death was possible. However, her perception of illness as an acute problem with a cure seemed to provide her with strength. Her view of recurrence as an acute episode seemed to help her persevere.

Repeated crises of cancer often meant unpleasant bodily sensations, frequent treatment that might require hospitalisation, disrupted social life, and alterations in the family's life in general, as evidenced in chapter 4. Attempting to change these situations was inherently difficult, if not impossible, and in many cases, it appeared that acceptance was part of a rational approach to persevere, as described next:

Everybody around me is also suffering, they feel sorry, very sorry, but when a problem comes along, you have to deal with it, and take it as well as you can go on (Patient 4)

Facing a second recurrence might require a different attitude compared to the approach used in the previous experience of recurrent cancer. For example, a woman who had had surgery and chemotherapy to treat bone metastases in her femur described her way of coping with second relapse as follows:

It took me approximately a month to readjust, and, if previously it had been an external rebel force, this time it was a readjustment as a pact with the illness.

CGV: Like accepting the illness?

Yes, you accept it as if it was an unfriendly guest you have to put up with, because you cannot send him away, as: Go away! You are ruining my life! Because then, it causes an action-reaction defence. Sometimes you think, ok, you are here the shortest possible time, I want you here as short a time as possible, during the time you are here, I am going to treat you well, between brackets, but only for you to leave earlier. I mean, I don't want you to stay for much longer, but during that period of time we'll have to live with each other. In that way, it took me almost a month and a half (Patient 6)

Here, the use of the metaphor of making a pact with cancer shows the way this woman rebuilt morale through accepting cancer. In this extract, cancer was personified as an unwelcome guest who invited himself to stay for a time and ended up moving in. With this metaphor, the woman expressed that cancer was part of her life and she had to deal with it, if life was to go on.

In a similar way to patients, family members expressed words of perseverance. When I asked the son-in-law of a patient about his main concerns, he shrugged his shoulders and said:

It is life. Life is like this, and life is as it comes and life is how you decide to fight it (Son-in-law 12)

A renewal of hope reported by most of the patients and families was apparent, as described by the next nurse in agreement with the other nurses in this study:

This illness in these patients, sometimes we can see an amazing capacity for fighting, to continue fighting and even more, always having hope, every patient, they always have hope (Nurse 10)

Overall, the families described their will to keep going. However, some of the families, especially the patients who were experiencing unpleasant physical symptoms at the time of the interview had more difficulty grasping their motivation to persevere. Dealing with long-lasting suffering seemed to entail wavering, from discouragement when physically worse to strength when physically improved. Demoralisation and hope came and went to allow perseverance to endure. This is what Nesse has called *The evolution of hope and despair* (Nesse 1999), where “hope and despair exist in the middle realm, when efforts are ongoing but the goal is not yet reached nor recognised as impossible” (p. 441-442). Others have characterised hope as a dynamic process in which hope interacts with despair (Kylma & Vehvilainen-Julkunen 1997, Morse & Doberneck 1995b). Patients in this study talked about this dynamic process of enjoyment and suffering which was greatly influenced by their physical and emotional conditions. Because of the interdependent and reciprocal dynamics of patients and family members, the responses of one affected the other. In the same way as suffering has been found to be an interactive process within the families, the maintenance of patients’ hope had a contagious effect on the family members and the nurses.

It is noteworthy that vacillation between hope and demoralisation was balanced within the families. When comparing the data on patients and family members, I found that in none of the families were all their members disheartened. On the contrary, when the patient was down, the rest of relatives bolstered the patient’s hope, and vice versa; when the relatives were in low spirits, the patient reinforced the relatives’ hope. This dynamic of hope is in agreement with Morse’s and Doberneck’s delineation of the concept of hope (Morse & Doberneck 1995b). Among the seven

components of hope, “the solicitation of mutually supportive relationships” was described as:

The attainment of a goal was not achieved alone but within the individual's support system. Within this system, individuals usually “balanced” each other, so that when one person needed of encouragement, someone else would give it. Later, these roles might be reversed (Morse & Doberneck, 1995, p. 12)

Signs of hope were observed among the three groups of participants. Hope was intrinsic in order to move on through the long trajectory and the exhaustion of treatment. Minor indication of hope contributed to deal with obstacles and difficulties encountered in the experience of cancer. This is demonstrated in the next extract:

I hope that if it's not this treatment that cures it, it'll be something else. Go ahead! (Patient 11)

In the darkness of the experience of recurrence, this extract shows the constructive meaning of maintaining hope. Although individuals expressed hope in varying ways, a perceived sense of possibilities was important to maintain hope, also discussed in the literature (Ersek 1992).

Faced with the reality of recurrence, the patients were motivated to deal with new treatment and uncertainties. Hope seemed to allow patients to find positive meaning in their actions as they moved away from focusing on tragedy to embracing what was possible, as described with humour by a patient:

Plans for the future? Wow! If I still feel ok, I'll continue living and with enthusiasm, what are you going to do? Me, right now, that thing bout throwing myself onto the railway line is not appealing (Patient 12)

The above patient who was 78 years old had survived 13 years without evidence of the disease before he was diagnosed with recurrence. Though shocked by relapse, he accepted his diagnosis positively. His response to recurrence might be influenced to a

certain degree by his age. For someone in his/her seventies, coping with an existential crisis might be a possibility in view of the future. However, it was very different for younger patients. Having a recurrence at a young age was associated with greater worries and distress (as described in chapter 4).

Repeated successful resolution of experiences with cancer facilitated the maintenance of hope. For one patient who had had a short-term remission before he was diagnosed with a distant recurrent cancer, looking to the past and recognising that things went well reinforced his willingness to face the present:

You endure it, and it can be endured, that's why I say certain optimism. You look back and say, "Well this will end too"
(Patient 13)

This patient reported having had a good experience of previous cancer because he had not been "too much affected" by the side effects of treatment. He felt comfort on comparing his experience with past cancer because he realised that cancer had been solved positively. The comparison between the past incident with cancer and the present experience with recurrence encouraged him to continue fighting. For another patient, who had gone through the experience of two cancer recurrences, looking to the future and having confidence in the effectiveness of new cancer treatment provided her with a sense of hope regarding her fear of a third recurrence:

Well, I'd be afraid of having it spread and that it might re-appear, but it's not something that's on my list of possibilities at the moment. I feel the situation has been overcome and will be overcome for quite a while. I mean, maybe forever. Let's say that my feelings about the situation at the moment are optimistic (Patient 6)

This extract highlights anticipation of fear of recurrence while in treatment. Along with the woman's fear of the spread of cancer, she expressed relief by being positive about the future. Having gone through repeated experiences with cancer seemed to provide her with the capacity to find resolution in advance and allow her to view the future with optimism. Her husband also seemed to have a conviction that future

difficulties might be overcome. The relative's response to the question "How do you feel after going through this situation again?" is a good illustration of his permanent hope for the future:

I feel quite calm, don't I? Now almost, not at first, but later I have a certain feeling of calm and hope, almost is a little, if you like it is a subjective vision, but the fact of having got over it the first time and the second, you say, "Well, it almost looks as though I can get over it indefinitely" (Spouse 6)

For this relative, the fact of having gone through a previous recurrence resulted in him acquiring a sense of perseverance to deal with cancer over time. Similarly, nurses observed a continued attempt of the families to persevere. When asked about her perceptions of caring for patients with recurrent cancer, one of the nurses, who had been working in cancer care for 14 years, captures the view of many nurses about patients' perseverance:

Often [I'm] surprised because it's bad news and although at the beginning they take it badly, they soon get on with it very well...they adapt again to starting the new cycles and all that (Nurse 7)

Although initially the patients and their relatives might feel demoralised because of the shock of the diagnosis and disbelief in treatment effectiveness, the nurses recognised the families' ability to create a sense of continuity and persevere despite difficulty.

In conclusion, a commonly held view for all the patients and family members was the belief that they had no choice but to accept recurrence. Accordingly, the families approached recurrence by wavering between feelings of hope and demoralisation. Far from being limiting, this change of emotions helped the families to move forward. When the families allowed themselves time, they probably found meaning within the experience of recurrence. On this issue, spirituality was found to be an important source of personal meaning; see below.

SPIRITUALITY

In this study, the role of spirituality was positive for some families in controlling overwhelming feelings of demoralisation because it gave individuals certain expectations about the future. The word *spirituality* was not only synonymous with religious practice but had other significance, such as the search for existential meaning within the experience of recurrence. This finding is in agreement with other studies that have proposed a holistic view of spirituality that is broader than religion (Oldnall 1996, Strang *et al.* 2002). Spirituality has been defined as:

A personal search for meaning and purpose in life, which may or may not be related to religion...This connection brings faith, hope, peace, and empowerment. The results are joy, forgiveness of oneself and others, awareness and acceptance of hardship and mortality, a heightened sense of physical and emotional wellbeing, and the ability to transcend beyond the infirmities of existence (Tanyi 2002, p. 506)

It is noteworthy that religion played a large role in the dimension of spirituality in this study. This may be explained by the fact that the family-oriented culture of Spanish society has a marked Christian origin. There were participants who expressed their faith in God to describe what hope was for them. For example, a spouse emphasised her husband's faith as an important tool of strength to deal with recurrence:

He is very religious, with great faith (Spouse 10)

This patient attached a religious significance to hope. Having had the possibility of practicing his religion within hospital, and even fulfilling his religious wishes of receiving the Sacrament of Anointing of the Sick on two occasions, seemed to provide him with great fortitude, as explained by his wife.

When asked about his plans for the future after the end of his wife's treatment for recurrent ovarian cancer, a spouse responded:

I have faith, I have faith, and I trust in that faith. And when these things happen, what will be, will be, and if they turn out badly, they do...That's life! (Spouse 3)

The extract above highlights how hope and religious beliefs were uplifting. Trusting in God and having faith provided the spouse with a sense of calm and confidence for the future. Similarly, the next two patients described how religion provided them with a sense of control and comforting thoughts, especially when death was perceived as a possibility:

Well, I think about the everyday, that [God] will help me, that He will give me a hand, that I will be able to live tranquilly, and that what is going to happen in these last years, I hope to enjoy them (Patient 4)

I am a believer and if my time has come, well I have to accept it... here I am with my faith and God and very content to leave this world. Yet, I don't want to go, I really want to live! (Patient 12)

Others believed in destiny. In the comment of a patient suffering from rectal recurrent cancer, hope was perceived as a kind of confidence that things would turn out well:

I'm convinced that I'll get better, I mean I've convinced myself, to try and accept it. Of course there are nights when, I usually sleep well, but sometimes you think you're dying, I've thought so often. And I've even lost all fear of that, fear, of course, and dread, I think, "Well, if it's to happen, it will". And I have also believed and still believe in fate (Patient 13)

This patient held an existential meaning of spirituality that helped him to bring the possibility of death back to the idealism of the future. In other words, creating meaning from acknowledging what could be, seemed to empower him to persevere through accepting the future.

In summary, the role of spirituality promoted persevering despite recognising that life could be shortened. The different shapes of spirituality helped the families in reformulating pathways to hope and in deciding to be strong.

SUFFERING, GROWTH, AND CANCER: GAINING EXPERIENCE FROM THE PAST

This category illustrates the families' secondary benefits of having a recurrence of cancer. Developing learning experiences from cancer seemed to facilitate preparation for the future. The process of becoming "skilled" in managing cancer helped understand recurrence, resulting in the families developing abilities to confront challenges.

Suffering from cancer also appeared to be constructive and might even give more significance to life. Recurrence seemed instrumental to the development of behavioural strategies which are important for understanding the experience of suffering. When asked if there was any difference between the first cancer and recurrence, a young family member responded:

Sure, we're all having a bad time, but it's not as bad as the first time, now we're more, we have more experience, and we know how to face it (Son 7)

Acquiring knowledge from previous experiences with cancer might facilitate achieving a greater sense of direction, as indicated by a patient:

You know where you're going and you also know that you have to go through bad times, you know what to expect (Patient 14)

Previous experiences of cancer seemed to facilitate adaptation to recurrence because "there was a preparation" that helped families to have some control over the situation. Other patients found open communication about their disease essential.

Their desire and need to be informed about all aspects related to their cancer provided them with strength to fight against it.

Surprisingly, a patient with a second recurrence talked about the gift of cancer in her life. When asked if she had gained something from the illness, she explained:

A lot: the illness, my attitude, yes, everything; and well, other people's attitudes. Yes, each time I've come out of the illness better, in spite of all the enormous physical losses because it's been very cruel. I was young when I started, and it's been very cruel... your hair, your femininity isn't there, the impossibility of having children; I mean the price was high but I've received more than I paid. I owe nothing to the disease, although of course there are things that bother me (Patient 6)

The above extract illustrates the woman's understanding in relation to significant physical losses due to cancer. However, the woman seemed to put her suffering within a larger perspective, allowing her to move on and even identify growth from cancer. During the interview, she stressed that she found herself to be another person thanks to the disease. The notion of the self was changed by the cancer experience, to say that the woman changed her view of cancer from being potentially fatal to offering her benefits and a positive experience. Positive changes regarding "becoming another" constituted for this patient a more gratifying relationship with herself:

I'm different, and grateful to the disease, to the cancer, grateful... Because if there's one thing I'm clear about, it's that the three times I've come out of it better each time. Personally, better and better (Patient 6)

This extract shows that repeated recurrences made the woman grow stronger. Although initial emotions might be overwhelming, she used the crisis of recurrence as an opportunity for further maturation. Therefore, recurrence might bring benefits such as great personal growth.

Some patients reported having developed a deeper understanding of life and even recognised the importance of cancer in their lives. Besides, the life-threatening nature of cancer recurrence provided an opportunity for patients to review their life and to appreciate small things more; some of them postulated a profound realisation about what was important in life and what was secondary:

Before you worried about every little thing and I'm terribly house-proud, but not any more. You realise there are things that are of no importance... I think my scale of values has changed a little (Patient 15)

Others believed that cancer had made them a better person because they had had the opportunity to help others in a similar situation:

I was a kind, loving person or I enjoyed helping people before [cancer] and that, but now it's three times better. Giving love to people, helping as much as I can, I love it (Patient 9)

Consistent with these findings, research reveals that patients with chronic illnesses may experience beneficial outcomes from negative events such as a relapse. For example, a study exploring the experiences of patients with multiple sclerosis, lupus, and cancer in relation to potential psychosocial benefits from their illness, found that benefit was related to adaptive coping approaches such as positive reappraisal and enlisting social support in patients with multiple sclerosis (Mohr *et al.* 1999). Besides, in patients with cancer and lupus, benefit was related to a greater appreciation for life and more compassion for others, these aspects being associated with reduced emotional distress, more vitality, and lower pain level (Katz *et al.* 2001). An important implication of the findings of the present research is that patients may experience benefits from suffering from a recurrence of cancer particularly.

In addition to having a deeper understanding of life, some family members reported having acquired serenity to deal with stressful situations. To the question “is there

any difference in coping between the first time and the current time?” a family member replied:

Well, you have more serenity now (Spouse 10)

The spouse of a woman finishing treatment for a second recurrence used the example of maturity to illustrate the process of learning to deal with repeated recurrences:

You often don't know exactly what inner resources will develop, do you? What the inner tools are. What is true is that you find yourself face-to-face with a problem and you don't know how, but you find some of the tools and you say, "What are these tools?" It's a bit like trying to describe maturity. It is what makes you react one way when you face up to a difficult situation or find yourself in a similar situation some time afterwards and you react in a different way (Spouse 6)

Similar to the process of personal maturity, he described serenity as being required to display certain attitudes as part of the process of maturity toward cancer. According to the spouse, acquiring serenity helped to recognise the emotional tools that worked in the past and discard those that had not. Rather than viewing the crisis of cancer as a failure, this spouse identified the situation as a way of acquiring skills and capabilities to cope with difficult conditions. This extract also adds to the understanding which emerged from this study that time and experience affected how the families experienced recurrence. The more frequently families experienced cancer seemed to match up with the patients' and relatives' ability to manage the effects of cancer and its treatment. Families had some idea about how to make such experiences not as bad or they knew how to make one feel in control over the situation to some degree. A nurse corroborated with the fact that families learnt through the experiences:

They [patients] are already involved in this world...they feel upset but not shocked. They accept it, of course they don't accept it happily because it's like the disease is worse, of course they are upset, it's bad news, but I don't think it's so

dreadful or shocking for the patient as at the beginning
(Nurse 3)

However, as shown in previous sections, there were times where even the most experienced patients or family member had problems reducing suffering. Key phrases such as “it’s so hard”, “it’s too long”, and “I suffer” were often expressed by the patients and family members and were indicative of the fact that families, although doing their best to adapt to recurrence, experienced great suffering during this phase of cancer. Living with cancer recurrence was characterised as experiencing intense emotional dynamics between demoralisation and hope and losses and gains. In this atmosphere of suffering, professionals might be able to alleviate some of this suffering. The following section describes the families’ view of nursing care as a source of support during recurrence.

The human side of nursing care

In a previous section, it has been shown that family relationship was an important source for rebuilding morale. In illness, another source of support was the health professionals. *The human side of nursing care* describes the families’ encounters with nurses. The category is structured into three related subcategories.

The first has been labelled “*cariño*”: *human qualities of nurses*, and illustrates the patients’ and family members’ perceptions about the qualities of nurses. The Spanish word “*cariño*”, which may be translated as affection, kindness, or love, has been used to describe and explain the families’ perception of nursing care. An alternative label could have been used to name this category, however, I decided to keep the Spanish word for two main reasons. First, the Spanish term reflects the participants’ perception of affection regarding care more deeply and clearly. Second, the use of the original word echoes the participants’ voices and contributes to the credibility of the findings (described in chapter 3). The second subcategory has been entitled *human caring as the cornerstone of supportive care for patients*, and describes the

view of the families on the interpersonal processes and relationships between nurses and families. Finally, the third subcategory entitled *patients' relatives: is nursing supportive to family members?* explores the relatives' perceptions of the support they received from nurses.

“CARIÑO”: HUMAN QUALITIES OF NURSES

The concept of “cariño” developed from the beginning of the study and was often the response to the question: “Could you tell me what are your perceptions of the care you are receiving from nurses during hospitalisation?” An initial answer to the question referred to the good care patients were receiving and how satisfied the families were with the nursing care. Indeed, all the patients and the majority of relatives stated that there were no suggestions for improvement when I asked them what else they would like to receive from nurses during hospitalisation. As the conversation followed, a main concept related to “cariño” emerged referring to the importance of nursing warmth and affection during treatment for recurrent cancer. The patients and their family stressed that, in addition to nursing skills about treatment-related management, the human attitude was a main characteristic of nursing care. It was also interesting to note that the families often centred their response on the nurses' personal qualities. This may be because they usually thought about a particular nurse when describing how nurses cared for them while in the hospital.

A wide range of descriptions was used to express affection from nurses. A 52-year-old woman undergoing chemotherapy for a third recurrence explained the tough time she had experienced during treatment for her second relapse. The bone marrow transplantation she had was especially painful for her and her family because she had had severe side effects that were life-threatening. When she reported her view of nursing care during this time, she said:

Those girls [nurses] looked after me so well; I mean I'll never forget it! (Patient 9)

This extract reflects the woman's appreciation of the special care of nurses during her stay in hospital. Next, I asked her about the type of care that she considered most important from nursing. She responded:

Their love, kindness, their love (Patient 9)

Nearly all the patients and relatives in the first interviews used the word love ("cariño" in Spanish) to describe nursing care. In an attempt to reach the exact meaning of the word, I asked the following patients to explain in more detail what the word meant for them. A woman undergoing treatment for pancreatic relapse described it as follows:

They spoil you, they do everything with so much love, they are never short with you, and they're always saying, "Is something wrong? Don't you feel well? Do you feel faint?" That's great for someone who is ill (Patient 11)

Frequently, the family members shared the view of patients about nursing care based on kindness. For example, some family members judged that quality in nursing was not about the precise care itself, but about the person giving this care:

Kindness, lots of kindness, there is kindness, I don't know, it must be humanity. I think they show it just because they're like that. Do you see what I mean? On the one hand, you have the profession, and the kindness you see in a person on the other (Spouse 2)

This extract indicates that the husband perceived nurses to be compassionate. Interestingly, he differentiated between nurses' competence and kindness. It seems that the spouse did not expect kindness to be provided by nurses and he perceived it as something extra. Similarly, a patient saw affection as separate from professional competence:

Wonderful, I don't only mean professionally, it's the human contact (Patient 9)

Another patient associated a competent nurse with a professional providing both physical and emotional care. He used grades to point out the characteristic features of good nurses, as show below:

There are A's and A pluses.

CGV: What's the difference?

Well, it's a set of things: she[nurse] is such a good professional and psychologically even better. She communicates; apart from the fact that you can ask her questions, she has skills; we might say love (Patient 13)

Here, the patient describes nurses in terms of their professional standards, including their management of treatment and physical problems, and their personal qualities and manners. The patient identified as a good nurse the professional who encouraged open communication and had an affectionate attitude. Other ways the patients underlined the human qualities of nursing care were as follows:

I think [the nurses] have excellent human qualities (Patient 1)

They are all very affectionate, very human, very concerned, and always ready to talk about everything (Patient 3)

These two patients were referring to the human qualities of nurses as associated with a supportive approach. One of the patients recognised affection from nurses as central for her:

Affection, affection, the affection they give you, is the most important thing for me (Patient 3)

Likewise, most of the family members perceived the nature of social interaction between nurses and patients to be an important aspect of nursing quality care. Seeing how their relative was cared for with love and fondness contributed to the fact that family members identified nursing as an important source of support for the patients.

For example, a 24-year-old daughter identified nurses' gentleness in handling hygiene care as valuable and positive for her mother:

That tenderness helps her; they do things for her with so much affection. They don't wash her just like that, but with so much affection (Daughter 2)

Overall, the patients and their family agreed with the view that an affectionate approach was important during cancer care. The families valued the caring relationship between nurses and their relatives, and most importantly, they appreciated that their relative was treated as a *person*. This attitude was mentioned as useful and encouraging communication between nurses and patients, as show below.

HUMAN CARING AS THE CORNERSTONE OF SUPPORTIVE CARE FOR PATIENTS

In an attempt to explore the value of nursing care in relation to adaptation to recurrence, I asked patients and family members separately if they would expect any other type of care that they had not received during their stay. Surprisingly, the majority of them reported their satisfaction with care in general, and nursing care in particular. In subsequent questions, I tried to explore how nurses helped patients during recurrence. A 45-year-old patient explained:

When they've seen me feeling [ill], obviously they are very busy, but when they've seen me feeling down they've come to see me, they've come often ... and sit at the foot of the bed and, "How are you? What's up that you look down? What's up today?", and that has helped me (Patient 3)

The above woman was experiencing great suffering because she had been diagnosed with recurrent ovarian cancer three months prior to the interview. She expressed feelings of loneliness because she could not speak openly about her condition with her family, particularly with her mother who did not know about this new diagnosis. In addition, she deeply feared death because she had a young child who needed her. When considering her situation, the woman described the positive benefits of being

able to share her worries and concerns with some nurses. By taking time to be with her, engaging in conversation, and providing her with emotional support when it was most needed, the nurses seemed to be supportive to the woman.

Although it is not the aim of this research to compare centres, many of the patients and family members who were interviewed in the University Clinic referred to other hospitals to highlight the empathetic qualities of nurses. Thus, in the next extracts, I do not wish to contrast quality of care between centres, but to underline the characteristic of kindness that the families believed to be important during treatment for recurrent cancer. For example, a patient in treatment for a first recurrent cancer explained the reason of this difference as follows:

It's not the same thing at all, being here with nurses who look after you, are affectionate, comfort you, help you, as being somewhere else where the people are cold and seem to find their job hard, no? Anyone can put you on a drip at any time, but there are many ways of doing it (Patient 3)

A spouse corroborated this observation in this way:

We are worlds apart, I don't mean they are not efficient, but their manner is short, they treat you properly, but there is no affection (Spouse 10)

Differences in nursing care were exclusively in relation to the nature of the interaction between patients and professionals. Similar to the families from the University Clinic that stressed their appreciation of the humanistic approach from both doctors and nurses, the families in the Public Hospital also highlighted the human qualities of nurses. For example, a patient said:

They cheer you up, they tell you how you'll feel, I don't know, you ask them a question and they answer very affectionately (Patient 11)

This patient described the attitude of nurses as helpful and kind. Later in the interview, the patient described the intrinsic and positive benefits from the nurses' caring attitudes that helped develop confidence and trust.

Being available to patients, referred to by patients and family members as "being there" emerged as a key aspect in the development of a caring relationship:

If I have any doubts they are there; with the doctors it's more difficult; but with them [nurses] you know you can ask them anything at all, they're there (Patient 14)

When we've needed them, they've always been there, what more do we want? (Spouse 9)

Taking time to be with patients and responding to any concerns related to cancer and its treatment were identified as important elements in the families' perception of nursing support. However, some patients pointed out that nurses were so busy that they were not as easily available as they would like. In addition, effective communication was reported to be important. Patients found receiving clear and accurate information about their disease invaluable. Indeed, one of the patients argued that having information was essential to understand the disease and to gain control over cancer.

Particularly, when the patients felt vulnerable because of the diagnosis of recurrence and difficult treatment, support from professionals combined with affection became central:

When you're well you don't want anybody's advice and you jump the barriers and so on; but when you are delicate, they help you, cheer you up about everything and it's a pleasure to come (Patient 12)

For this 78-year-old survivor who had recurred after being disease-free for 13 years, nurses' support helped him to feel comfortable and secure. Similarly, a patient highlighted the importance of emotional support:

I think the nurses are great, very positive; they give great moral and spiritual support, a lot (Patient 1)

The daughter of this patient reiterated on the benefits of nursing support for her mother:

My mother pours her heart out to them [nurses] more than to anyone else, because she thinks they are the best, they understand because of their wisdom, their studies, because they are close to people with problems, and they treat her and listen to her (Daughter 1)

Overall, the patients and their family members valued positively the human nature of nursing involving an affectionate approach, information support, and emotional support. However, two husbands pointed out the importance of differentiating between an affectionate approach and a childish attitude:

I believe the best help is good information and natural behaviour. They treat you as an equal, without too much affectation... Maybe I'm contradicting myself, not affectation, but personal human behaviour (Spouse 6)

He continued explaining how nurses should be supportive:

Their behaviour, if you like, rather than a child-parent relationship, is almost adult-adult, they treat you as an adult, but with closeness, with a certain amount of affection (Spouse 6)

This spouse spoke with appreciation about how a specific “adult to adult” approach on the part of the nurses was important in establishing a therapeutic relationship. According to him, expert nurses with several years in nursing practice seemed to have better knowledge on how to create a healing and supportive environment. On the contrary, he found that the infantile relationship that he associated with younger and less experienced nurses was detrimental. Although valuing affectionate relationship, another husband expressed his dissatisfaction with receiving childish care:

The support the nurse gives you is mental support, in the sense of affection. You see, what I admire is the human behaviour, the fact that they are involved with this woman or this man. And as they are ill, they have to be treated with great delicacy, not babying them, you see? (Spouse 3)

Therefore, the families perceived nurses' personal qualities and their affectionate, but not childish, relationship as helpful for the patients during treatment. Notably, nursing care was identified not merely as a task but as an integral process that involved interest in people, human qualities, and an affectionate approach. In this study, patients, family members, and nurses focused on the emotional and psychosocial aspects of care, as opposed to the physical aspects of care. This may be so because the questions the participants were asked centred attention on this particular aspect of nursing care. This is acceptable for this study which aimed to explore the type of support families perceived from nurses rather than to explore the physical care provided during cancer recurrence. Largely, a human approach was valued as supportive for the patients, but generally not for the family members. Accounts on this matter are presented in the next section.

PATIENTS' RELATIVES: IS NURSING SUPPORTIVE TO FAMILY MEMBERS?

The above section shows the satisfaction of both the patients and their family members regarding how nurses cared for the patient. More importantly, it shows the extent to which the families identified nursing as being supportive to most patients. The current section presents the view of relatives regarding the support that nurses provided to them as family members.

All the family members, except two spouses, identified nurses as supportive to patients but not to them. This was the case of a husband who found the hope that nurses gave him and his family during hospitalisation to be helpful:

Those kisses and these things help you to forget your misery. They say, "It'll all be all right", they give us patience, "It

works, it's hard, it'll all turn out all right, the liver tumour has disappeared". And that's what helps you to get through the day more easily, that hope they offer you (Spouse 2)

Support was not merely encouragement but also something with human caring implications that provided him with a sense of serenity and empowerment. This empowerment appeared to give this spouse the moral support necessary to continue along the cancer pathway. Another relative gave a general view of why she considered nurses were supportive with her:

They explain you what can happen, also the very positive attitude they have, it really helps you...First there is love, they are friendly, they put up with everything, I mean, you don't say anything to them, it's complicated, but they are very patient, they are kind, they console you (Spouse 10)

The above excerpt shows how important it was for this spouse to feel informed about future changes in the patient's health, to feel comforted, and all in all, feeling supported during a tough time. Indeed, when asked if she felt supported by nurses she replied:

Yes, as a member of the family, too. The nurses put up with me because this is really the only place I can talk... They listen and cheer me up (Spouse 10)

The above data show that some family members felt comforted by nurses; this feeling seemed to predict their satisfaction with the nursing quality of care.

In contrast, the majority of family members perceived their needs were unmet. Different reasons were given to explain why nurses were supportive to patients but not to family members. First, a lack of relationship with nurses prevented relatives from receiving nursing support:

They cannot help me at all, because I'm not here with them, we have no relationship (Daughter 1)

It is worth noting that it was the second time that the daughter came with her mother because her father, who generally accompanied the patient, was not available that day. Despite the above daughter's response, she was convinced that she would receive help from nurses if she asked for it, as another spouse indicated:

I don't ask for help, psychological or any other kind, but I suppose that if I asked, I imagine that they would at least encourage me or give me something as human beings (Spouse 7)

Surprisingly, the young son of the above relative explained the reasons for not asking for nursing support in this way:

I prefer them to look after my father, because I'm healthy, I'm perfectly well, then they should concentrate on my father... how his mouth is, if he's in good spirits, look after him... I am healthy, I can talk to my mother, or I can go for a stroll if I like... It's my father who cannot move; so all the attention should be for him (Son 7)

This relative preferred his father to be the centre of care. He was pleased that nurses met his father's physical and emotional needs rather than dealing with his concerns that he perceived as insignificant and easily solved compared to his father's needs.

A third reason that prevented family members from disclosing their concerns to nurses lay in relatives' understanding of the role of nursing:

The nurses, psychologically, have treated my wife marvellously...but psychologically, I've never thought it was logical to talk to the nurses; I've always thought the logical thing would be that a psychologist or psychiatrist should come and talk to me. What would I tell a nurse about? My life?...You can't talk about that to a nurse, I mean, there are people whose job is [psychological support] (Spouse 3)

Although the spouse recognised nurses as being supportive to his wife, he did not expect nurses to provide him with emotional support. He saw nurses as unqualified

to help family members emotionally and also, he considered other professionals should deal with the psychological concerns of families living with cancer.

In summary, family members characterised nursing dedicated to supporting and offering affectionate care to patients. Affectionate care was described by the families as care that emphasised the human qualities of nurses based on affection, feeling cared for as a person, knowing that nurses were available, and a human approach to caring. Moreover, two family members perceived nurses as supportive with them in terms of giving affection, being hopeful, and raising their morale to deal with cancer recurrence. However, most of the family members did not benefit from nursing support either because they did not disclose their concerns and fears to nurses, it was more important to meet the patients' needs, or it was not the role of nursing to provide emotional support to family members. The next section will add information about the nurse-family relationship as perceived by the nurses.

Towards boosting families' morale after a recurrence

This category describes how nurses worked with families in an attempt to help them acquire enough strength to adapt to recurrence. Similar to the families, the nurses recognised recurrence as an ongoing struggle that required a search for meaning and a great effort:

A recurrence means fighting on, for me as a nurse and as a person, I don't like to talk about a recurrence as the end of the line, as a thing, no, because I just couldn't go on. It's a constant struggle (Nurse 8)

This "constant struggle" involved nurses shifting the focus of care to give priority to emotional support. This approach was, however, particularly challenging for nurses because of lack of skills and a heavy workload.

SHIFTING THE FOCUS OF CARE

Although the nurses found it difficult to offer a clear definition of what caring for individuals with recurrence involved, they frequently referred to many differences between newly diagnosed patients and patients with recurrent cancer. According to one nurse, recurrence had specific characteristics, so both patients and nurses had to deal with illness differently:

It's a completely different approach; at least that's how I see it. The illness is another illness, and you have to deal with it in a completely different way, both them [patients] and us [nurses] (Nurse 5)

All the nurses pointed out the fact that caring for patients with recurrent cancer was different. A nurse clarified this point by saying that the difference lay in the attitude of professionals:

The care, looking after them, doing things for them and talking, I look after them in the same way; but I think your attitude is, has to be different (Nurse 6)

Care should be different because the patient with a recurrence also had a different attitude toward the illness, as shown in the following extract:

It is different because the patient himself has a different attitude towards accepting the disease, that's what I think. And different, perhaps the person with the recurrence demands more of you, demands more care, more attention, they are in worse shape, they are more ill, well, I think [the difference] is mainly psychological (Nurse 11)

Each nurse sought to explain why care for patients with recurrent cancer was different from care of newly diagnosed patients, although they had difficulty in giving reasons. However, the data illustrate a common view of such difference: this was related to the amount of emotional support given to patients. According to a nurse with 7 years of experience in cancer nursing:

At a technical level, there is not much difference but at an emotional level, there's a big difference (Nurse 8)

The nurses generally identified information and education as the pillars of care when patients were diagnosed with cancer for the first time. In this case, the most common activities were associated with alleviating physical discomfort, educating about management of the side effects of treatment, and in general, addressing the patients' and family members' need of information. Hence, their effort focused on giving a series of details about the treatment:

With a new patient, I have to give them a lot of information. First about the treatment they will be getting, the injections, the effects it will have. I mean, they need to know lots of things (Nurse 6)

The focus on information could be so central that the nurse failed to ask about the patients' psychological condition, as one nurse indicated:

Maybe you don't notice the emotional state of a person with a new diagnosis to the same extent, because the newly-diagnosed cases that I have had are more worried about what chemotherapy is (Nurse 2)

All the nurses agreed that giving information about chemotherapy and educating patients about how to manage side effects of treatment was the best way to help newly diagnosed patients. In contrast, the nurses believed that patients with recurrent cancer did not require so much information, as patients had already gone through it all before and the situation was familiar for them. In the words of a nurse with 10 years of experience in cancer services:

In a recurrence, it's completely different because they know what chemotherapy is, and that at the end of the cycles they were exhausted. You can't just tell them, "Well, it's like this, cheer up because you'll be going home, you'll be leading a normal life". Yes, they will, but they know what it's like, it's not new to them (Nurse 3)

In addition, some nurses argued that patients diagnosed with recurrence often knew about the adverse effects of chemotherapy, and then they gave priority to emotional aspects of cancer:

They know what it's all about, and so they need more psychological support (Nurse 4)

Newly-diagnosed patients are full of doubt and the others [patients with recurrence] are more demoralised... in a recurrence they know all that and it's more like encouraging for them, I don't know, it's different. Some people fear the unknown and others already know too much; then, I think it's more emotional support (Nurse 7)

In addition to the importance of alleviating the physical discomfort of patients, all the nurses highlighted the importance of emotional care for patients with recurrence. The data also show that nurses did not consider information about treatment management as the centre of attention, though they also gave information to patients with recurrent cancer when needed. Rather, their pattern of care shifted from an informative and educational focus after the first diagnosis of cancer to a more supportive and emotional focus after the diagnosis of recurrence. Interestingly, none of the nurses suggested potential differences between patients with a first recurrence, a second, or more recurrences. As described earlier, the nurses did refer to the physical aspect of cancer occasionally. A possible reason was that physical care was taken for granted, so they talked little about this part of care. This might be because the nurses felt the need to speak about the emotional aspect of caring because they knew the interest of the research about the emotional impact of cancer recurrence. Despite this, the findings of this study evidence that nurses perceived emotional care to be essential in caring for patients with recurrent cancer. More information on this matter is presented in the following sections.

GIVING PRIORITY TO PSYCHOLOGICAL CARE

Nurses identified different types of support to help patients deal with the course of illness. Besides providing medication and physical care, important aspects of caring involved being with and listening to patients:

Every time we go [into the room] well we have to stay there. I mean, it's not just taking him [the patient] pills, but being there with him all the time, watching a symptom or a sign, or simply watching the expression on his face and being there both for him and his family (Nurse 4)

As the analysis of the data moved on, I felt it was important to ask nurses about the distinction between cancer patients with recurrence and terminal patients. Therefore, I introduced the question “Is there any difference between a patient with recurrence and a terminal patient?” This new question would help me to clarify needs of patients depending on the phase they were in the cancer trajectory. One nurse responded in terms of treatment differences. As she said, patients with a recurrence restarted a new course of chemotherapy whereas terminal patients did not receive active treatment. However, my interest was in exploring the differences from a nursing perspective rather than from a medical perspective. Thus, I asked for detail about the characteristics of the nurse-patient relationship in cancer recurrence and in the terminal phase. After some indecision, she answered:

Well then, [silence] when you're dealing with a patient with a recurrence, there are more things you can say to him/her, true? [laughs], not just saying, “Don't worry, calm down, the medication did you good (Nurse 14)

The nurse used the term “medication” to refer to drugs that palliated physical pain or discomfort. In the context of the interview, the above extract seems to suggest that the nurse associated the recurrent phase of cancer with possible survival. “There are more things you can say” seems to show that the patient had a chance of recovery. In contrast, the palliative phase was associated to the problem of no recovery.

Giving priority to psychological care after recurrence involved fostering hope in the patients:

I personally go into the room more often to ask how they are, or to try and cheer them up (Nurse 2)

I think you have to give them a lot of support, persuade them not to give in, to keep on fighting like I said, with all the strength they can (Nurse 8)

For a nurse with 33 years of experience in cancer care, giving hope to the patient consisted of helping them recover trust in treatment:

What I try to do is to give a little more faith, medically speaking, to make them believe a bit more. If a patient has a very early recurrence, they don't believe in the chemo because the last time it was useless to them. They start by losing a little faith in the treatment (Nurse 13)

According to some nurses, it was important to foster hope but the most important factor was being realistic about the particular condition of the patients. On occasion, the nurses might be hesitant to provide hope because they feared giving false expectations:

You are a little frightened of encouraging them, in inverted commas, of giving them reasonable hope, and that later it may go wrong (Nurse 2)

To avoid communication problems about diagnosis and prognosis, some nurses used the strategy of only informing about what the doctors had said during the visit.

Some nurses also pointed out about the importance of dealing with the existential concerns of the patients. Experience was identified as motivator of knowing how to deal with spiritual and existential issues, as evidenced in the next extracts:

Experience is a degree in this [caring in the recurrence] but it's an important degree (Nurse 8)

With time, at least I've learned to listen to the patient (Nurse 3)

However, experience alone was insufficient. The main barriers, including inadequate training in psychological matters and workload, were influential in creating a healing environment. Most of the nurses pointed out a lack of knowledge about how to deal with patients' suffering or what to say to them. The training they received as students equipped them principally for technical aspects of dealing with cancer. However, concerning psychological issues, most of them said they were unprepared to give effective psychological care:

We are very well prepared to carry out our nursing techniques, but psychologically, I think we need people to teach us how to deal with these subjects and to answer correctly, so that you don't feel: "Now what do I say?" (Nurse 1)

I have experience with cancer patients, but from the emotional point of view, we have no training, it's not professional training (Nurse 6)

In contrast, both experts and novices felt confident when managing the physical facet of the disease because they had been well trained in procedures:

I look after them very well physically, if they need to change position, if they need a pain-killer, I'm coming now, I lower their temperature, in that sense I know I can do it, that the patient is well looked after. Psychologically, with a recurrence, I have to sit down with a person, first I don't have time, but if I had, where would I start and what would I say, how would I encourage them, and in what direction, because that is also part of the care and attention I have to give (Nurse 3)

The above extract reflects the understanding that caring for patients with recurrent cancer required addressing the emotional needs in addition to meeting physical needs. The data show that the nurses were limited to providing holistic care that included physical and psychosocial care because of inadequate skills, although they

recognised the importance of supportive care for patients with recurrence and their families. Bearing in mind this limitation, the nurses did their best to support patients emotionally:

We nurses try to give as much emotional support as we can, but basically I think it's a problem of, I think, a lack in our training (Nurse 6)

Sometimes you tell yourself you're doing all you can, but I don't think this is how we should be helping (Nurse 8)

When nurses felt they did not have sufficient skills to help patients dealing with emotional suffering, they often turned to other professionals, such as psycho-oncologists.

In addition, workload was a major concern for the quality of support. The issue of busyness, referred to by a nurse as “there are times when you want to talk, but you can't, you just can't, because all the bells are ringing” (Nurse 1), could leave nurses little or no time to sit with patients and listen to them. When patients and their families considered nurses busy, it might hinder effective communication and a sense of lack of supportive nursing care, as pointed out by one patient:

They haven't time, not because they don't want to, but because there are so many people, and they have so much work (Patient 6)

Overall, the nurses believed the emotional aspect of cancer was priority when caring for patients with recurrent cancer. Emotional support consisted of “being with and listening”, promoting realistic hope, and dealing with existential and spiritual awareness. However, a lack of skills in psycho-oncology and a heavy workload were two main barriers to supportive care. While all efforts were made to support patients, there was little attempt to help family members master recurrence.

MORE NEEDS TO BE DONE FOR FAMILY MEMBERS OF CANCER PATIENTS

All the nurses agreed about the fact that family members of the patient with a recurrence had their own needs, and they would require attention from nursing staff. However, several factors prevented nurses from dealing with the family members' needs.

First, some nurses commented family members were more concerned with the patients' suffering than with their own suffering. Consistent with the data from some family members, nurses reported relatives generally requested information about the patient's medical condition and treatment effectiveness:

The family members above all ask us, not about them, but about medical matters and how it's going... what prospects there are, what treatment is to be used (Nurse 2)

The family members' need for information might be met but relatives still had emotional needs. A nurse referred to a survey she conducted about the impact of cancer on family members. She found that caregivers did not only experience psychological needs but also physical needs, such as stress-related constipation and problems sleeping. Then, she stressed the importance of supporting family members as well:

You have to think of the relative as another patient. Their needs are different from those of the patient.

CGV: How would you go about dealing with their psychological needs?

By supporting them, listening to them, understanding that if the patient is afraid, so is the relative (Nurse 8)

Additional comments made by nurses were indicative of the difficult time family members were experiencing. Yet, the nurses often did not address the family members' suffering:

The family normally doesn't [get any help], they may be given some anti-anxiety medication, but that trust that is needed to understand how they feel, if they are crying or are depressed, very infrequently (Nurse 2)

This extract and the data presented earlier suggest that the quality of the support offered to the family members differed from that given to the patients. It seemed that the degree and type of nursing support was unsatisfactory for most of the family members. This may suggest that families felt unsupported, a feeling that may add to the harsh experience related to dealing with cancer recurrence. These findings are consistent with other studies that have indicated that insufficient emotional support is given to relatives who accompany hospitalised patients (Ästedt-Kurki *et al.* 1999, Eriksson & Lauri 2000, Kristjanson & Ashcroft 1994). Although studies have considered family members' suffering (Wright 1997), there is insufficient information on this matter. That is one of the reasons why the present study has paid great interest to depicting the experiences of family members in relation to their suffering during the recurrent phase of cancer.

In addition, nurses referred to space and time as limiting care for family members. It is important to point out that the day unit of the Public Hospital was organised to hold a small group of patients in a large room full of patients and medical staff. This meant that the nurses did not have a private place to meet with relatives. In contrast, the three settings in the University Clinic had rooms where the patients and their family members could be together and where the nurses could discuss things with the family. However, the nurses of both hospitals reported space, or rather the lack of it, as a factor that limited support for family members as desired. These findings suggest that the patient's room was taboo for discussion with the family, an aspect related with the conspiracy of silence discussed in chapter 4, and also illustrated in other research (Ozdogan *et al.* 2004).

Overall, nurses recognised the need to support family members because they have their own psychological needs in addition to concerns for their ill relative. However, a common pattern of nurses was to focus principally for the patients, sometimes to

the point that a simple aspect such as knowing the name of the relative might be neglected by nurses, as indicated by one of them. It was unusual for nurses to invite family members to determine what recurrence entailed for the family. A possible reason for this attitude is that the nurses chose to focus on the provision of information about procedures and treatments as a protective mechanism against emotional and existential concerns, more difficult to deal with (Kruijver *et al.* 2001, Sines 1995). Other factors limiting support for the families were lack of skills to manage emotional issues in cancer and heavy workloads.

Summary

As a result of a diagnosis of recurrence, the families faced changes in their lives that required different sources of strength to deal with the aspects of exhaustion, uncertainty, and reawakening of the fear of death. The concept of *rebuilding morale* emerged in this study to explain the psychological and social processes carried out by the families to adapt to recurrence. Morale in this instance emerged as that essence that helped families persevere to get through the challenges of cancer recurrence.

Throughout the process of constant comparative analysis, it became apparent that there was a relationship between previous experience of cancer and current experience with recurrence. The families talked about the means they used to adapt to recurrence referring to their previous experiences with cancer. Besides, adaptation to recurrence was partly integrated in concepts such as family strength, perseverance, personal growth, and the human side of nursing care. Indeed, nursing was found to play a role in the families' cancer trajectory. The data have shown that the majority of patients and their family members perceived a human caring response to suffering to be supportive for the patients. In shifting the focus of care toward giving priority to psychological care, nurses helped patients rebuild morale over the recurrence. Yet, most of the family members perceived support for them to be inadequate, and the nurses coincided.

Other important findings of this study are:

- ✓ Each participant has an individual and unique experience that is co-built by a relationship with others and the world.
- ✓ Cancer recurrence is a phase of the cancer trajectory that begins with fear of recurrence.
- ✓ Cancer recurrence occurs within the family, meaning that not only is it a patient's individual experience, but it is also a family experience.
- ✓ Demoralisation is an emotional response of individuals to recurring suffering.
- ✓ Demoralisation is characterised by exhaustion, reawakening of fear of death and fear of the unknown.
- ✓ Nursing care is recognised to be supportive to patients but not to family members.
- ✓ Management of the emotional aspect of cancer is challenging for nurses, partly due to lack of skills in psycho-oncology and heavy workloads.

In view of the fact that the impact of a recurrence on the patients and family members is associated with great suffering, including demoralisation, it is critical to plan therapeutic care that may help both patients with recurrent cancer and their family members master the illness and life in general. In an attempt to help nurses care for families during a cancer recurrence, I have developed a new understanding grounded in the data of this study. The next chapter presents a theoretical proposal on family suffering.

CHAPTER 7

DEMORALISATION IN CANCER RECURRENCE: A PROPOSED THEORY FOR FAMILY NURSING

Introduction

The findings of the last three chapters give readers a greater understanding of the impact a cancer recurrence had on the entire family, and new knowledge of the experiences of nurses interacting with these families. Despite the diversity of participants' personal and social characteristics, it was important to find out in how many ways similarities between the groups were manifested about the phenomenon of cancer recurrence. The current chapter presents an interpretation of the responses of the participants regarding the phenomenon of cancer recurrence.

Theories and models help define the meaning of a particular event, how it works, and whom it involves. Theories are sets of statements that aim to describe, explain, or predict the relationships between concepts. However, conceptual models or frameworks, which are often referred to by authors as interchangeable, are sets of concepts that symbolise a relationship between the concepts that have emerged from the interpretation of a phenomenon (Hanson *et al.* 2005). It is important to find models that can complement our current understanding of an event and improve our practice (Polit & Beck 2004). Models have emerged that explain the psychosocial aspects of chronic illness. For example, *The Chronic Illness Trajectory Framework* (Woog 1992) has been important in practice to improve care in chronic conditions. In the cancer arena, models have emerged that explain the psychosocial aspects of cancer (Dorsett 1992), contributing to knowledge of the experience of cancer. Nursing has traditionally used models from other disciplines such as sociology to complement understanding of illness behaviour (Kelly 2003, Young 2004). Applying

theoretical assumptions from other disciplines has been beneficial in helping nurses conduct research. However, the profession of nursing, in addition to borrowing theories from other fields, should generate its own knowledge to improve nursing care in particular, as nursing theorists have increasingly been doing.

Grounded theorists can aim to generate formal or substantive theories (Glaser & Strauss 1967). A formal theory deals with a general and abstract domain of inquiry as the abovementioned *Chronic Illness Trajectory Framework*. In contrast, a substantive theory, also referred to as mid-range theory in nursing research (Meleis 1997), focuses on a more particular, more limited domain, and addresses specific phenomena (Glaser & Strauss 1967). *The Trajectory of Cancer Recovery* is an example of substantive theory that describes the specific cancer phase of remission (Dorsett 1992).

For a theory to be useful, it must articulate a set of statements that provide an understanding of what the concepts are, how and why they are related, who is involved, and when and where the concepts are applicable (George & Jones 2000, p. 658). The current study attempts to develop a comprehensive substantive theory that offers new understanding of the psychosocial processes of families facing cancer recurrence and nurses caring for them during recurrence, with the hope that it can improve nursing care in this phase of cancer. The centrality of the family in the experience of recurrence, and the link of the experience with temporal terms, emerged from the data as main concepts in the social construction of the meaning of recurrence. Therefore, I considered it appropriate to guide the development of the emerging theory using the assumptions of the family as a unit of care, and temporality, as a foundation for the experience of cancer recurrence. In this context, two theoretical frameworks known as *Family Nursing Theory* and *Social Theory of Time* were used as a means of questioning the data in the emergent theoretical proposal. These frameworks are briefly outlined below.

Family Nursing Theory, based on the principles of Systems Theory, considers the family as a system that is organised and unique, and the whole is greater than the sum of its parts (Hanson & Boyd 1996, Hanson *et al.* 2005, Whyte 1997). The

members of the family are interdependent and the unit is in constant interaction to adapt to stresses from the external environment and changes from the internal family environment (Hanson *et al.* 2005). In this study, the descriptions of the participants indicated that when one member of the family experienced recurrence of the illness, the family unit was affected. The crisis of recurrence was a critical event in the life of families because the family's functioning might change. However, families manifested unique physical, emotional, and social patterns which were in constant flux to adapt to the differing experiences of recurrence. Therefore, it is important that nurses work collaboratively with families and help them identify their strengths. This is one of the pillars of family nursing which considers not just the needs of the patients and the other family members, but the needs of the family as a whole (Whyte 1997). An assumption within family nursing care is that professionals should help the families recognise their abilities to solve problems and cope with their own challenges. This strength-orientation will be discussed later.

Social Theory of Time proposed by the social theorist and sociologist Barbara Adam considers the symbolic representation of time in terms of past, present, and future dimensions (Adam 1990). Understanding Adam's theory appeared to be the most appropriate method in the emergence of this theoretical proposal because it emphasises the subjective experience of time. Thus, a person constructs her experience of recurrence as connecting past, present, and future and as perceiving the nature and experience of time (e.g. the perception of temporal duration). Adam (1995) identified three elements of time: temporality, timing, and tempo. Temporality refers to the cycle of life and death that is characterised by the irreversible linear nature of temporality inherent in life. Temporality further emphasises the relationship between the past, the present, and the future which contributes to how individuals organise and plan their lifetime. Patients and spouses recalled their first experiences with cancer to explain the present recurrence. In addition, events were anticipated in a potential future. Temporality was also seen in accounts of families when they spoke of enjoying daily life because of the uncertainty of the future. The element of timing concerns the times given by clocks and calendars (e.g. follow-up visit at 10am on Friday 9th January). Finally, tempo

involves the combination of temporality and timing and how they progress at various speeds (Adam 1995). A practical example of the tempo frame is when the families spoke of time being too long (in chapter 5). In developing the proposed theory, aspects of time will be further discussed in this chapter.

Demoralisation in cancer recurrence is the proposed theory grounded in the data. The theory attempts to define what the experience of cancer recurrence involved for families and nurses from a psychosocial perspective. It also provides direction in comprehending how families experience cancer recurrence, so that nurses can address the potential needs of patients and family members during this phase of cancer.

The proposal conceptualises caring for families with a cancer recurrence as involving three main elements or categories. These categories are related to chapters 4, 5, and 6 of this work respectively. The first emergent category is called *the suffering of families facing cancer recurrence*. The findings suggest that understanding the experiences of recurrence of the families seemed important for recognising the nature of family suffering. Distinguishing demoralisation from other types of distress is important for nurses in caring for families, and if possible, in the alleviation of their suffering. The second category is identified as *towards a new conceptualisation of demoralisation*. In contrast with the concepts of distress and depression which have received abundant attention in cancer research, little is known about demoralisation. Therefore, I present an original insight into the experience of demoralisation in the context of cancer. *Family nursing: supporting families to manage recurrence of cancer* is the last category that suggests interventions that may assist families adapt to recurrence of the illness.

The suffering of families facing cancer recurrence

Since nurses are at the bedside throughout the course of the cancer trajectory (Ferrell *et al.* 2003), they are often an important support for those suffering. Thus,

understanding suffering and the individual's response to suffering is at the heart of nursing care (Morse 2001). However, before suffering can be alleviated, it must be understood (Lindholm & Eriksson 1993).

A reminder is appropriate here about the extension of suffering in this study. Suffering has been found to be reciprocal and socially constructed. Thus, in trying to fully understand the experience of recurrence within the family, there is a corresponding need to be familiar with the patients' and their relatives' experiences of suffering.

DISTRESS FOLLOWING CANCER RECURRENCE

Considerable suffering is associated with cancer and there is evidence that significant others shared this suffering (Lindholm *et al.* 2002, Sherman 1998). There are different ways of classifying suffering. One way associated with cancer is psychological distress. The National Comprehensive Cancer Network (NCCN) Distress Guidelines for patients (National Comprehensive Cancer Network 2005a) defines distress as follows:

Unpleasant feelings or emotions that may interfere with your ability to cope with cancer, its physical symptoms, and its treatment. Distress covers a wide range of feelings, from powerlessness, sadness, and fear to depression, anxiety, and panic (p.5)

This definition shows that distress is a general concept that includes anxiety, depression, and fears caused by a threatening event like cancer. It is important to recognise the types of distress that patients with recurrent cancer and their family members may experience, because lack of insight into the psychosocial experience of recurrence can prevent professionals from devising effective approaches to family care. The findings of this study cannot provide statistics about the type of psychological distress associated with recurrence because the interest of the research was not to measure distress. Rather this study explored the emotional impact of

individuals confronting recurrence. Interviews as a channel for communication were useful to express feelings and emotions. Therefore, reported information is about the *qualitative experience of distress* as described by the participants and not about the clinical diagnosis of distress that is subsumed under the rubrics of Diagnostic and Statistical Manual of Mental Disorders (DSM) and the Diagnostic Criteria for Psychosomatic Research (DCPR).

Feelings of anxiety and depression have been identified as common types of distress experienced by cancer patients and families (Gil *et al.* 2005, Ozono *et al.* 2005). Studies have found significant prevalence rates of psychosocial distress within the cancer population (Jacobsen *et al.* 2005, Kua 2005, Okamura *et al.* 2000, Zabora *et al.* 2001). A distinctive form of distress referred to as *post-traumatic stress disorder* (PTSD) appears relevant among cancer survivors (Black & White 2005, Butler *et al.* 2005). Research about the complex processes of surviving cancer has permitted increasing understanding of the short and long-term effects of unrelieved suffering associated with cancer (Brown *et al.* 2003, Yabroff *et al.* 2004). A growing literature documents the sequelae confronting survivors of cancer, including fear of recurrence (Cameron *et al.* 1998, Lee-Jones *et al.* 1997, Ullrich *et al.* 2003), physical problems (Dorval *et al.* 1998), and psychosocial concerns (Charles K 1996, Mast 1998, Thewes *et al.* 2004). Survivors of traumatic episodes, such as refugees, present similar psychological sequelae that have been increasingly described as PTSD (Vargas *et al.* 2004, Zarowsky 2004). While it is appropriate to refer to the type of distress which survivors of a traumatic event may experience because it is of relevance in this study, the focus of this section, however, is on describing distress among families facing recurrence of cancer.

Suffering is associated in this study with the relapse of the illness. A diagnosis of recurrent cancer represented a new crisis for patients and those close to them. The use of words denoting shock, devastation, and fear described the feelings of families as they recalled the early days after diagnosis of recurrent cancer and the present time with treatment. The diagnosis might bring back memories of treatment and anticipation of fears. In addition, loss of independence due to the effects of treatment

might contribute to anxiety in patients because of the need to rely on their family members. These results are consistent with the findings of Okamura *et al.* (2000) who found that psychological distress is associated with the diagnosis of recurrence of the disease. However, the present research in addition demonstrates that the impact of recurrence is not confined to the patients alone but that family members also felt its impact. The psychological and physical impact of the disease, the changes in roles, and the loss of dreams often created psychological distress in both patients and their key family members. For instance, children expressed anger and frustration as a result of their parent's illness (as observed in the interviews with daughters in family 1 and 2). Typically, spouses responded similarly when they found themselves facing repeated life-threatening crises.

There is no doubt that an important finding of this research is the social nature of psychological distress. Distress was found to be significant among spouses of patients with recurrent cancer. This was related to how recurrence intruded into the families' lives, altered the health status of the patient during treatment, led to worries about the future health of the patient, and increased uncertainty of the spouses about the future. The data evidence that often spouses experienced greater distress compared to the patients. Indeed, a great number of interviewed patients identified their spouse as the person most affected in the family following recurrence. These findings are consistent with research demonstrating that spouses of cancer patients are psychologically vulnerable, and that their emotional wellbeing may even be more impaired than that of patients (Harrison *et al.* 1995, Ozono *et al.* 2005). It may well be that patients who experience a recurrent cancer benefit from being the focus of the health care, whereas spouses and other family members are rather more isolated from the support of the oncology team, and consequently experience substantially greater anxiety, as shown in chapter 6.

The findings of this study, in agreement with other research (Byrne *et al.* 2002), indicate that most of the patients expressed the need to conceal their suffering from their loved ones to protect them. However, this mutual protection did not appear to lessen distress within the families; quite the opposite, it often resulted in the family

members suffering in isolation. The implication of these findings for clinical practice is the need to understand family dynamics in order to detect potential psychological distress due to a conspiracy of silence (this aspect will be further developed later).

A number of writers have attempted to explore the psychological impact of recurrent cancer as a source of distress in patients with recurrent cancer and their relatives. This has been dealt with in this study, but an additional perspective related to an unexplored phenomenon in nursing is presented next.

DEMORALISATION AS A FORM OF DISTRESS AFTER RECURRENT CANCER

The concept of demoralisation has made its appearance in diverse fields of psychology and psychiatry. The book *Persuasion & Healing* by Jerome D. Frank, co-authored by his daughter, deals with suffering that includes demoralisation (Frank & Frank 1991). This book is addressed to therapists to give them an understanding of the fundamental nature of psychotherapy. In medical literature, most of the papers published have examined the concept from the perspective of psychiatry (Clarke *et al.* 2005, De Figueiredo 2000). Recognition of its importance in oncology dates back only to the last decade (Angelino & Treisman 2001, Breitbart *et al.* 2000). In terms of its core features, some have identified demoralisation as comprising hopelessness, helplessness, loss of purpose and meaning, despair, and existential distress (Boscaglia & Clarke 2006). Many studies about demoralisation have identified the concept as a psychiatric reaction associated with poor outcomes, such as a precursor of serious depression (Rickelman 2002), and even a desire to die or to hasten death (Clarke & Kissane 2002, Kissane 2004).

However, the analysis of the data in this study reveals that demoralisation may be a form of distress in response to recurrent cancer (as I shall explain later). Thus, demoralisation is not associated with psychiatric morbidity but it is found to be a combination of past fears, present suffering, and anticipated uncertainty. The data show that recurrence is a challenging time for patients and family members. From a

retrospective view, this is because feelings of apprehension and worry due to fear of the cancer recurring is common among cancer survivors and their family. When diagnosis of recurrence is a fact, this time is stressful as recurrence often generates a great deal of uncertainty and suffering. The emotions that were elicited at the time of first diagnosis tend to recur and are intensified when fear of recurrence “becomes a reality”. As a result, cancer patients and their family members appear to experience emotional distress. Although the participants in this study did not refer directly to the term *demoralisation*, they referred frequently to many attitudes that according to the interpretation of the data form the basis of a demoralising experience. Therefore, in this study demoralisation means a form of distress caused by the impact of having cancer again.

DEMORALISATION VERSUS DEPRESSION

The opposing view of demoralisation in this study compared to the literature highlights the urgency of further exploration of the concept and the need for its comparison with other well-defined types of distress. Only recently, demoralisation has been differentiated from depression in the development and elaboration of a demoralisation scale (Kissane *et al.* 2004). Although the scale has only been subject to preliminary validation and needs confirmatory validation, as reported by its authors, initial evidence for a difference between the two concepts has been considered.

Depression is defined as generalised distress which is part of the DSM-IV classification of depressive disorders (American Psychiatric Association 1994). Others (National Comprehensive Cancer Network 2005b) define depression as “a psychiatric disorder characterized by sadness, lack of energy, loss of pleasure in usual activities, difficulty concentrating and making decisions, changes in appetite and sleep, hopelessness, and sometimes thoughts of suicide” (p.5). There are different diagnoses for depression that are determined by the intensity and duration of the symptoms and by the cause of depression (e.g. major depressive disorder,

recurrent depression, dysthymia, and bipolar disorder) (Kissane *et al.* 2004). Demoralisation has been proposed as a relevant psychiatric diagnosis for palliative care (Kissane *et al.* 2001). Kissane and colleagues (2001, p.15) suggest six diagnostic criteria for demoralisation that include for instance, feelings of hopelessness and loss of meaning and purpose in life, feelings of helplessness and lacking a worthwhile future, and social isolation. The authors indicate further that the emotional intensity of these feelings can vary in time but demoralisation should persist at least two weeks. Besides, a major depression or other psychiatric disorder should not be present as the primary condition. Although Kissane has attempted to evidence that demoralisation is a distinct psychiatric diagnosis, there is still poor evidence on this matter. Four years later after his publication of demoralisation as a relevant psychiatric diagnosis for palliative care, the author himself suggested that “further research into demoralisation is needed before it should be broadly adopted as a valid expression of illness”(Kissane 2005). This suggests that there is almost no evidence yet that demoralisation is a distinct psychiatric diagnosis.

The different perspective of demoralisation in this study encourages the need for detailed clarification of the concept following to the emerging understanding stemmed from this research. Demoralisation is defined in this work as involving six main characteristics. The characteristics are compared to symptoms of depression described in the literature in an attempt to show readers the differences between the concepts (see Table 7). The defined characteristics are as follows:

- 1) Demoralisation has been found to be a psychological response to the impact of facing cancer again. On the contrary, depression is related to a pathological state due to an overwhelming event (Kessler 1997), or depressive disorders such as bipolar disorder and substance-induced depression (Cervera-Enguix 2004).
- 2) As a form of distress, demoralisation is associated with disease recurrence, requiring management of new treatment on the part of the patients and reorganisation of social roles on the part of the family.

However, depression is often associated with advanced disease (Breitbart *et al.* 2000).

- 3) Demoralisation comprises emotions such as exhaustion, fear, and uncertainty. Feelings of exhaustion are characterised by the perception of enduring suffering due to cancer and its treatment. Fear is a result of uncontrollable outcomes in the future, such as uncertainty of treatment effectiveness and the unpredictability of cancer, which also lead to awareness of death. In contrast, depressed people experience feelings of sadness and hopelessness, and even thoughts of suicide (Beck *et al.* 1975, Breitbart *et al.* 2000, Massie *et al.* 1994).
- 4) In this study, the patients and family members, with few exceptions, did not seem having lost interest in life. Most of them expressed their desire to finish treatment and to continue the battle with cancer. There were several examples in which the patients and their family members showed their capacity for pleasure. For example, many patients expressed enjoying time with their children and spouses and keeping busy with friends. However, depressed people may express a lack of pleasure in life (Ingram & Scher 1998). This is because a person with depression has lost the ability to experience pleasure generally, whereas a person experiencing demoralisation, while being unable to look forward with pleasant anticipation, may laugh and enjoy the present moment, as participants did in this study.
- 5) Interpretation of the data reveals that patients and family members were uncertain about the future, so their effort focused on developing a meaningful present and “living the present in full”. The continued interest in living, expressed in the making of plans in a short time interval, showed the participants’ wish to continue the battle with cancer. Typically, the families showed great interest in the present but generally did not make long-term plans because of the uncertainty of the future. It is suggested that individuals centre their attention on the past and project to

the future to create the present. It is this looking back on unpleasant feelings and projection of uncertainty about the future that forms the experience of demoralisation in people facing repeated crises. In contrast, depressed people are able to plan for the future but they lack the motivation to do it (Ingram & Scher 1998).

- 6) Another difference comes from the type of treatment approach. According to Angelino and Treistan (2001), demoralisation is a form of suffering derived from a psychological reaction to a life stress that does not necessarily require psychiatric treatment. Because demoralisation is essentially psychological in nature, it is more responsive to supportive approaches, such as: psychotherapy, hope, therapeutic optimism, and time spend at the bedside. The proposal of this study is that a supportive approach may alleviate the experience of demoralisation among families living with a recurrence of cancer (as will be examined later). In contrast, depression is more physiological, thus a combination of psychiatric medication and psychotherapy appears adequate (Angelino & Treisman 2001).

The above discussion encourages distinguishing demoralisation as a symptom, a syndrome, or an illness, and demoralisation as an emotional experience when undergoing a painful event like a cancer recurrence. An example that may justify the importance of recognising the boundaries between normality and pathology is bereavement. Bereavement after the loss of a loved one is an emotional reaction that is considered normal, although it can become pathological when the emotion is endured and intense (Kissane *et al.* 1996). Research on grief and bereavement has influenced how the terms are conceptualised and treated as much has been learned about its physical and psychosocial processes (Chan *et al.* 2004, Golan 1981). Understanding how families grieve has been important to help families do so effectively. Yet, the concept of demoralisation has received little attention, and most of this attention is related to the concept to psychiatry and morbidity. Surprisingly, no paper has been found on the issue in nursing. Therefore, knowledge is lacking

about the meaning of demoralisation as an emotional response to the suffering of recurrence. For that reason, the aim of the next section is to develop a new conceptualisation of demoralisation.

DEMORALISATION	DEPRESSION
1) Related to a psychological response to repeated crisis.	1) Related to a pathological state due to an overwhelming event or not.
2) Associated with disease recurrence.	2) Associated with advanced disease and decline of health.
3) Feelings of exhaustion, fear, and awareness of death.	3) Hopelessness, sadness, and suicidal ideation.
4) Capacity to enjoy life. Able to express feelings (e.g. laugh).	4) Loss of interest to enjoy life. Lack of expression, apathy.
5) View of near future.	5) No sense of positive future.
6) Supportive care.	6) Psychiatric care.

Table 7. Differences between demoralisation and depression (based on data from Angelino & Treisman 2001, Beck *et al.* 1975, Breitbart *et al.* 2000, Cervera-Enguix 2004, Ingram & Scher 1998, Kessler 1997, Massie *et al.* 1994)

Towards a new conceptualisation of demoralisation

Research on demoralisation is controversial and indefinite as the concept has different definitions, ranging from general distress in response to life stresses (Angelino & Treisman 2001, p. 348) to a syndrome characterised by a sense of helplessness that may lead to thoughts of suicide (Kissane *et al.* 2001). Typically, literature on demoralisation is of interest in the world of psychiatry. However, a lack of interest in exploring the concept has been identified in psychiatric nursing, as

noted earlier. No paper in nursing, that I am aware of, has looked at demoralisation in cancer. Hence, the psychosocial meaning of the concept remains poorly explored in nursing in general, and in cancer nursing in particular.

Given the new conceptualisation of demoralisation that has emerged from this grounded theory study, I present an original understanding of the concept of demoralisation associated with temporal dimensions. Before doing this, I shall describe the characteristics of the recurrent phase of cancer that have emerged from this study. This is important for readers in order to comprehend the temporal dimensions of the experience of demoralisation.

EMOTIONAL PHASES IN THE RECURRENT PHASE OF CANCER

The experience of cancer recurrence has been identified in this study as consisting of three phases, which are linked with the past, the present, and the future (see Figure 10). These phases include the time before the diagnosis of recurrent cancer represented by the survival phase, the acute phase that comprises the diagnosis of recurrence and the treatment, and the recovery phase identified as remission.

The survival phase is the period that extends from the stage after the end of treatment for previous cancer and the time during tests before the person is told the diagnosis of recurrence. This phase has been found in this study to be marked by fear of recurrence because the person and his/her family may think cancer has recurred. The participants stated that their fear diminished gradually as the time since diagnosis was greater. Yet, the fear exacerbated just before follow-up visits, scans, and tests for cancer.

The acute phase starts after the diagnosis of recurrent cancer when families realise that the disease has come again. At this time, the patient and family members are initially shocked due to their understanding of the new diagnosis. Generally, they feel disappointed and angry while they seek to understand the situation (this was especially noted with the participants that I interviewed soon after diagnosis of

recurrence, e.g. patient 11 and patient 15). During treatment, families experience a period of turmoil with mixed feelings of exhaustion, uncertainty, and awareness of fear of death. This blend of emotions is brought together in this study under the concept of demoralisation. At the same time, the period of treatment, which extends from weeks to several months, is a period during which families try to adapt to recurrence while wavering between hope and uncertainty. This time is symbolised in this study as *rebuilding morale*.

In the recovery phase referred to as remission, the patients and their families may deal with the sequelae of recurrence, including the physical, emotional, social, spiritual, and financial ones. In particular, the families talked about the uncertainty of the future. However, this is only an interpretation of the participant's prospective view of the future because in this study all the patients were either initiating treatment or finishing it. Therefore, this phase should be further explored.

In the paradigm of the disease trajectory, a common course of cancer can be one of disease exacerbation followed by new remission and survival again (described in chapter 2). However, recurrence can continue with the progression of the illness that leads to the terminal phase of cancer and ends with death. This study has focused on the phase of treatment after recurrence, thus no information is available about the emotional aspects of the phases of remission after recurrent cancer, dissemination, and death.

TEMPORAL DIMENSIONS OF THE EXPERIENCE OF DEMORALISATION

This study has found that the experience of demoralisation during the recurrent phase of cancer is not an isolated event, but rather is a process that has duration and shape (see Figure 10). It has duration because the temporal elements of past, present, and future, are inseparable and interconnected. There is a past suffering, a present suffering, and an anticipated suffering. In order for the present experience of demoralisation to occur, previous experiences with suffering have to exist. That is, a

past experience of cancer constructs the present experience of recurrence. The future is no less meaningful for having not been yet; suffering is lived in the future since it forces confrontation with uncertainty.

It has shape as the nature of suffering varies through the experience of demoralisation. According to the data, there are three states, distinguishing *latent state*, *active state*, and *residual state*. The latent state, which I define as a condition that is potential but not evident, is characterised by fear of recurrence. This latent condition experienced during survival of cancer may develop into an active state characterised by initial signs of shock and cumulative suffering after a diagnosis of recurrent cancer. Periodic treatment for recurrent cancer that causes unpleasant symptoms adds to the existing suffering, contributing to exhaustion, both physical and emotional, uncertainty about effectiveness of therapy, and consequently, fear of the unknown and reawakening of the fear of death, as illustrated in Figure 10. In this context, I define the active state as a present condition limited in duration and with an identified cause as is the knowledge of facing cancer again. In contrast, the residual state remains as cancer therapy is being completed and remission is close. This state of demoralisation is characterised by uncertainty. Here, an important differentiation regarding uncertainty needs clarification. The nature of uncertainty differs according to the phase of cancer. Uncertainty during survivorship is related to the fear of recurrence that entails anticipation of unpleasant sensations. However, uncertainty after a diagnosis of recurrence is associated with lack of confidence in treatment and the unpredictability of cancer, and awareness of fear of death. Further, uncertainty about remission is related to fear of an unknown future.

Although the experience of demoralisation is related to suffering, it is also in itself conducive to adaptation to recurrence, as shown in chapter 6. After the diagnosis of recurrence, the families try to rebuild morale through family support, perseverance, and nursing support in an attempt to find meaning in the experience of recurrence. In other words, demoralisation is temporal as it may become latent when recurrent cancer is successfully treated or the experience of recurrence is slightly forgotten. However, if demoralisation is enduring, it can move into psychological problems that

may interfere with the ability to adapt to recurrence. This research has not assessed when a person became demoralised and I do not know the extent to which there is an association between having recurrence and becoming demoralised. This was not the aim of this qualitative study. Instead, this research has found that it is the individuals' perception of the cancer trajectory as indefinite which makes the experience of recurrence demoralising.

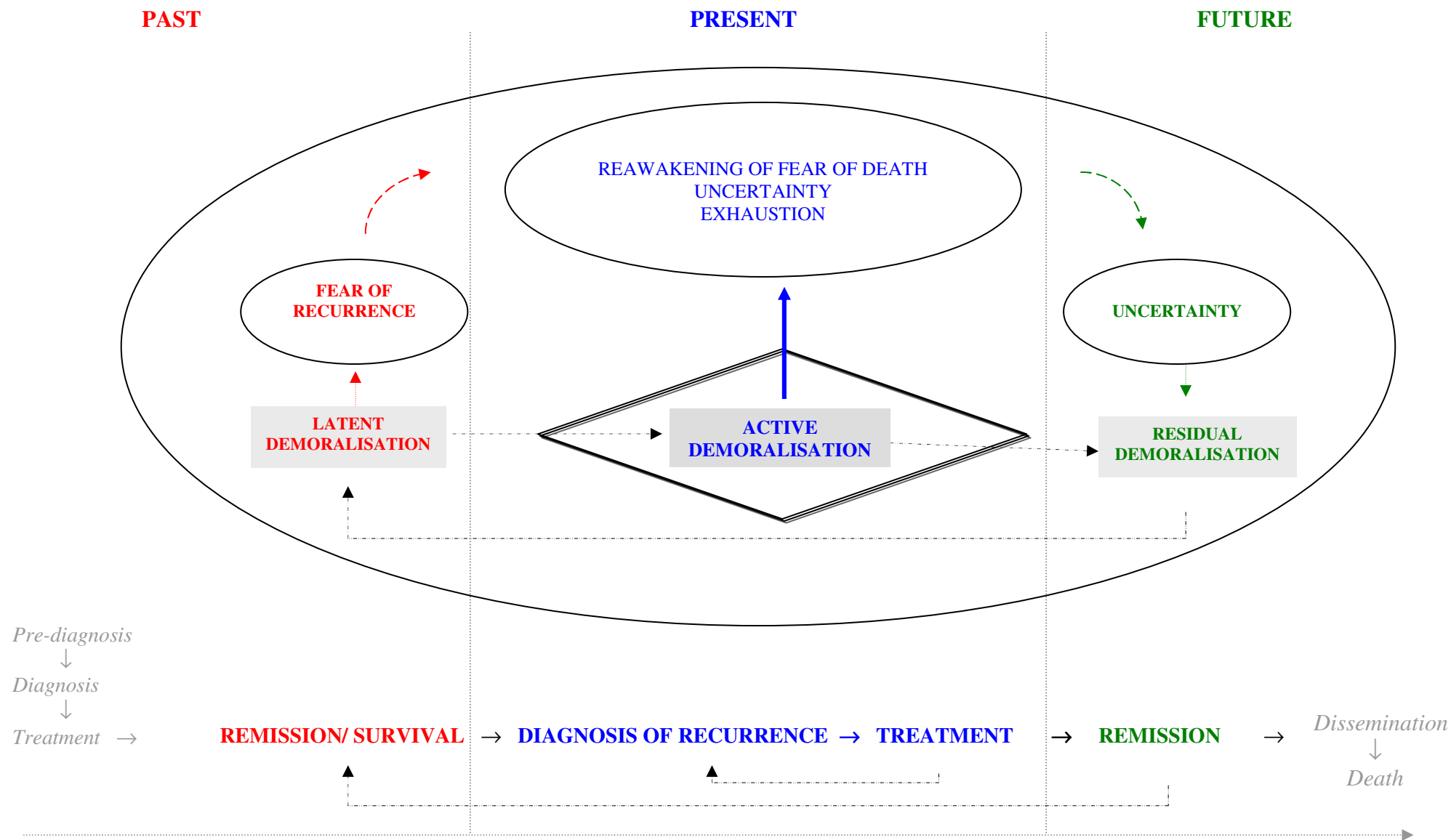
When individuals are concerned with the possibility of recurrence they fear and worry; when they are informed of recurrent cancer, they feel exhausted and uncertain about the future. Hence, the experience of demoralisation occurs as a response to the past experience of suffering due to the fear of recurrence, the exhaustion of having cancer again and the sustained uncertainty about the course of the illness and the future. These results reflect a sense that time is an essential aspect in the experience of demoralisation. In a corresponding view, two psychotherapists, Jerome D. Frank and his daughter, have developed a conceptual framework for psychotherapy in which they highlight the importance of time and uncertainty in the experience of demoralisation:

In general, when a person knows how to cope with a particular stress, or when the stress is well defined and time-limited, it will seem a surmountable challenge...By contrast, stresses with demoralising meanings lack a clear solution and are often expected to last indefinitely. Examples include chronic illness or persistent unemployment (Frank & Frank 1991, p. 23)

Dealing with a chronic illness may be demoralising because of the temporal projection of the disease and the uncertainty of its progression. Correspondingly, dealing with the crisis of recurrence seems intimately connected to a demoralising process. The “indefinite” aspect depicted in the above description is not the case in cancer recurrence as recurrence is a phase of the cancer trajectory, meaning that patients will move towards remission and survivorship or towards palliation and death. Yet, the feeling of the families that the journey is endless has been presented in chapter 5 as a subcategory named “*this is too long*”. Therefore, it is the perception

of a never-ending journey that makes the experience of cancer recurrence demoralising. In addition, the cyclical nature of the demoralisation arrows in Figure 10 denotes that the emotional response to recurrent cancer occurs and recurs in subsequent relapses of the illness. The circle allows for comprehension of the experience of demoralisation as a dynamic, not fixed process. This can be stated because in this study, there was a varying sample of patients with a first recurrent cancer, patients with a second recurrence, and one patient in treatment for a third recurrent cancer.

In summary, the emerging understanding of the concept of demoralisation proposes that demoralisation evolves over time. Demoralisation as a hallmark of a cancer recurrence is a present experience that has its roots in the past and its ramifications in the future. In accordance with Adam's theory of time in terms of continuity, the experience of demoralisation in recurrence is perceived as a now, but it has past and future dimensions. In this temporal context, time is conceived in a non-linear concept where the past and the future dwell in the present. Although these findings require verification and testing by other researchers, they have implications for caring for families during recurrence as they give good reason for supporting families before, during, and after a diagnosis of recurrence (as will be presented shortly).



The Cancer Trajectory

Figure. 10 Temporal dimensions and characteristics of demoralisation in the cancer trajectory

DEFINITION OF DEMORALISATION

Based on the findings of this research, I identify demoralisation in the context of a cancer recurrence as having the following characteristics:

1. A type of suffering that is experienced by a person or a group.
2. Results from previous suffering that is repeated.
3. An integrative emotion blending physical, psychological, social, and spiritual elements, which can be experienced by a group of individuals sharing a similar threatening situation.
4. Temporal duration.
5. A human experience that is related to repeated threatening situations.
6. A normal emotional response to endured suffering but which can develop into a psychological disorder when it prevents adaptation to a stressful situation.
7. Health professionals may alleviate demoralisation through supportive care (this point will be justified later in the chapter).

Demoralisation is conceptualised here as a transitional process that is experienced at some point in the illness trajectory. It occurs when one has had a previous life-threatening experience with cancer and this life-threatening experience returns. It results in the stimulation of suffering because of the accumulation of past suffering and the reviving uncertainty that is accompanied by the threat of death. The combination of the above characteristics provides the following definition of demoralisation which emerged from the data:

Demoralisation is an emotional response of a person or group of people to a repeated threatening event. Frequent signs of demoralisation in cancer recurrence include fear, exhaustion, uncertainty, and awareness of death. Demoralisation as a result of cancer recurrence can be

generally considered as a normal response to recurrent suffering.

Whereas some individuals may respond to recurrence in a dysfunctional way, such as developing depression, other individuals adjust to recurrence normally although this does not mean that they are immune to significant suffering, as this study has evidenced. Different conditions or factors seem to influence individuals' response to recurrence, as I present next.

CONDITIONS MODIFYING THE EXPERIENCE OF DEMORALISATION

This study has found several conditions (also referred to as attributes in grounded theory) that may likely influence the experience of demoralisation. These conditions include past experience(s) with cancer, length of survival, number of relapses and type of recurrence, age and gender, and social support. It is important that the oncology team be aware of these conditions in order to help families deal with demoralisation and cancer recurrence.

PAST EXPERIENCE WITH CANCER

The interpretation of past experiences with cancer seemed to be important and affect how the patients and the family members understood a recurrence of cancer, also highlighted in other research (Richer & Ezer 2000), and subsequently how demoralisation was experienced. A negative memory of cancer might likely contribute to high levels of distress due to anticipatory suffering. For instance, if past experience was traumatic because of difficult treatment, recurrence might be a more stressful event for both patients and family members. The underlying reason is that they might remember the tough experience they went through and they might anticipate emotional suffering. In contrast, those individuals having a more positive experience tended to compare recurrence with their first cancer and showed a

different approach to illness. The findings potentially suggested that the experience of demoralisation might be associated positively with an optimistic memory of the experience of cancer. Inversely, the more negative the memory of cancer, the more intense demoralisation might be. This observation, however, requires careful interpretation because the data presented here are an interpretation of the participants' subjective descriptions of demoralisation, but the degree of demoralisation was not measured. In addition, the way families saw recurrence seemed a critical factor in family adaptation. When families understood the situation as manageable and meaningful, demoralisation decreased (see family 6 and 9).

LENGTH OF SURVIVAL

An interesting observation from the current research was that the impact of recurrence depended to some extent on the duration of survival. Distress seemed to be intense for patients and families with a brief period of remission from cancer. This may be associated with an understanding by the families that the disease had not been totally controlled and that life was threatened by the illness again. Given the qualitative nature of this research, this observation should be interpreted cautiously before it is tested in comparative studies with short-term and long-term cancer survivors who are diagnosed with recurrent cancer. However, it is important to highlight that this remark is consistent with a quantitative study that assessed the prevalence of psychological distress in breast cancer patients with a first recurrence (Okamura *et al.* 2000). The authors found that women with a disease-free interval shorter than 24 months significantly predicted a diagnosis of major depression disorder. Although the sample size of the study was small to confirm that there was an association between psychological distress after breast cancer recurrence and a shorter disease-free interval, the study was relevant for the oncology team because it emphasised the importance of paying attention to the psychological health of patients with a diagnosis of recurrent cancer.

NUMBER OF RELAPSES AND TYPE OF RECURRENCE

The number of recurrences experienced was believed to be an important element in how the patients and the family members perceived the impact of a recurrence. Families in their first experience with recurrence seemed to be more of the opinion that recurrence had had a tremendous impact on their lives and this made the experience more demoralising. In contrast, families facing their second or third recurrence recognised demoralisation in the initial period after diagnosis of recurrent cancer but seemed to find meaning in suffering more rapidly. The families' view of the situation of recurrence as manageable seemed to provide them with a feeling of control of their lives which in turn provided a feeling of being comforted in a way that alleviated suffering.

The site of the recurrence was also found to be a factor that might influence the experience of demoralisation. The type of recurrence, including local, regional, and distant recurrence, seemed to change the meaning the families attributed to the relapse of the illness. Typically, families identified a regional and distant recurrence with more pathology, leading to increased awareness of death. In this situation, the families generally showed more intense reactions of demoralisation compared with families dealing with local recurrence. Perhaps families facing local recurrence believed they might have more chances of being cured compared to families confronting a distant recurrence. This explanation should be interpreted with caution as all cancers are different and recurrence is multi-causal as described earlier in the literature review.

AGE AND GENDER

Younger families, which were defined in this study as young couples with young and adolescent children, showed intense reactions of demoralisation (exhaustion, uncertainty, fear). However, older families, that is, couples with adult children, showed less intense reactions of demoralisation. Again, this observation should be

interpreted carefully due to the qualitative nature of the study. However, it was important to see that a quantitative investigation found that being under 50 years of age was significantly associated with having major psychological distress in patients with recurrent breast cancer (Okamura *et al.* 2000). In a study conducted with young and old cancer survivors which investigated the age-related needs of the women, the authors concluded that younger women reported more psychosocial needs than their older counterparts (Thewes *et al.* 2004). The findings from this research and the complementary literature reflect the difficulty young patients, and consequently young families, may have in adapting to recurrence. Recurrence may add to an already heavy burden of caring for school-age children while simultaneously fulfilling family obligations. It may be that older families, who have achieved a sense of overall family life control, may find meaning earlier.

The wife/mother plays a central role in the functioning of the family. This study showed that changes in family rules and responsibilities occurred as a result of the diagnosis of recurrence of a family member. It was further noted that when the patient was the wife/mother, the family lifestyles were significantly influenced. Changes included accepting new responsibilities for the house, the family, the care of children, and the care of the ill wife/mother. It was found that this situation could make the experience of demoralisation more intense because of the feeling of not controlling the situation.

The relationship between age and gender and demoralisation has not been previously described and requires further study. However, nurses must pay attention to the needs of younger families that may have greater psychological needs. Besides, nurses need to assess how families are managing at home and they also need to provide opportunities for family members to discuss the challenges they face in their attempts to reorganise family life as they learn to adapt to recurrence.

SOCIAL SUPPORT

Support from close family members was found to be beneficial to patients and families to find meaning and purpose in life, as shown in the section entitled *the family as a resource*. All patients spoke about the importance of receiving support and love from their spouses, children, parents, extended family, and close friends. Family members also described accounts of the importance of kinship support within the family. Increasing support in a person's life usually had a positive effect on the families' strength, which in turn helped them to feel better. Support was positive for families because it helped them to have a sense of meaning, control, and optimism (see for example family 2, 4, 6, 8, and 15). It has been found that emotions were often hidden among Spanish families in order to maintain harmony and welfare within the family. Yet, avoiding talking about cancer-related issues and not sharing emotions contributed to the suffering of the families. In this situation, feelings of demoralisation may be more intense because of the difficulty of discussing fear of death and uncertainties openly.

Extensive research has been conducted on the beneficial effects of formal support groups on both physiological and psychosocial outcomes in cancer patients (Cain *et al.* 1986, Samarel *et al.* 1998). None of the families reported visiting support groups although one patient and her husband (family 3) expressed their wish to contact them. The patient felt her suffering might be alleviated if she had someone to whom she could talk about her worries and suffering openly. The husband felt unsupported and alone and suggested that psychological support should be part of routine care offered to both cancer patients and their relatives. This observation increases our awareness of the support that must be given if professionals are to effectively work with and care for families at all phases of the cancer trajectory.

Another source of support was the nursing environment. For example, families might find involvement with nurses to be an important source of emotional support, particularly for patients. During treatment for recurrence, the caring approach from nurses was recognised as supportive; it helped most of the patients move forward with treatment. A great deal of emphasis was placed on helping patients to explore

their emotional concerns by encouraging them to talk about their most personal feelings. This communication approach seemed positive in dealing with demoralisation caused by recurrence. Yet, such approach often did not occur with relatives, resulting in their feeling alone and even more demoralised than the patients themselves.

Family nursing: supporting families to manage recurrence of cancer

It is widely recognised that family members give emotional support to their ill member, as demonstrated in this study. However, relatives should be also recipients of nursing care. This research has evidenced the profound impact that a recurrence had on all the members of the family. Family members might have many needs and might require help in dealing with their emotional wellbeing. Despite health carers' consideration of the importance of the family in cancer services, a gap remains in addressing the impact of cancer on family members in formal and recognised ways, except in palliative services (Kissane 1999). In failing to meet the needs of families with cancer, I believe there is a corresponding failure to provide holistic care in cancer services. An underlying finding from this research is that more might be achieved in the care of cancer patients if the family was considered as an entity needing care. Effective assistance for cancer families requires a careful consideration of a multidisciplinary approach in which a variety of therapeutic interventions can work together to improve health. Nursing, which plays an important role in cancer care (Ferrell *et al.* 2003), can make an important contribution to quality of life of families living with a recurrence of cancer. A major practice in hospice care is a commitment to provide comprehensive care for dying people and for their loved ones. Nursing in collaboration with the palliative team provide counselling and bereavement support (Skilbeck & Payne 2003). As in palliative care where attention is paid to the protection of a holistic and compassionate ideology (Bruera & Lawlor 1998, Mok & Chiu 2004, NCRI 2004), the same philosophy should be promoted in

the care for people at the different stages of cancer, including recurrence. The assumption is that both the patients with recurrent cancer and their family members should be viewed as the *unit of care* because they are part of the experience of recurrence, as this research evidenced. Health professionals need to understand the multiple perceptions and realities that exist within a family. It is only through considering the uniqueness of the experience of each family that professionals would be able to identify families' needs and to use this information to plan supportive care for families facing a recurrent cancer.

It is considered important to clarify the meaning of supportive care. According to a recent guidance published by the National Institute of Clinical Excellence, supportive care:

Helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement (NICE 2004, p. 17).

This section draws on the findings of this study to propose consideration of an integrated approach to supporting families deal with latent, active, and residual demoralisation during the experience of cancer recurrence. The discussion is organised into four parts. Part one, referred to as *nursing follow-up during cancer survivorship*, provides justifications for the use of a nursing approach to help families reduce latent demoralisation and manage long-term sequelae of cancer during the period of survival. Part two, entitled *looking for the whole: assessment of the impact of recurrence on the family*, aims to determine the nature and extent of the family's wellbeing to understand them and decide whether support is appropriate and, if so, what form it should take. Part three, categorised as *working with families to manage demoralisation* explains approaches to deal with active and residual demoralisation, which has been found to be characterised by signs of exhaustion, uncertainty, and reawakening of the fear of death. The assumption for this proposal is that supportive care from nurses can help the families experiencing recurrence to regain morale and adapt to cancer again. The last category identified as *meeting nurse's challenges in*

effective cancer care describes areas in which healthcare services should pay attention to the training and support for cancer nurses.

NURSING FOLLOW-UP DURING CANCER SURVIVORSHIP

Patients and family members experienced latent demoralisation before the diagnosis of recurrent cancer. These findings support the need to extend healthcare services beyond treatment and to encompass supportive care during family cancer survivorship. This is because the families' reports of fear of recurrence when they described their experiences during cancer survivorship retrospectively, evidence difficult experiences that may need the support of health professionals to better adapt to the illness trajectory. A comprehensive cancer follow-up may be appropriate for families during remission and survival. In addition to the traditional medical follow-up approach that is often based on the detection of recurrent cancer, I suggest the creation of a combined nursing follow-up care that would focus on psychosocial issues of cancer survivors and their families. There is a need for promoting appropriate management of psychosocial distress for families living with, through, and beyond cancer as well as a need for educating cancer survivors and their families about management of the physical sequelae of cancer and the warning signs of recurrent cancer. One recent suggestion of such an approach is the paper I wrote about long-term cancer care where I argued for the need to develop specific care for long-term cancer survivors (Vivar 2006a). Likewise, a nursing follow-up approach may be useful for short-term cancer survivors and their families in an attempt to reduce "latent demoralisation".

Besides, provision of a brochure which provides information about cancer recurrence and warning signs about when to visit an oncologist, information about coping styles, and stories of other families about survivorship, may be relevant in reducing psychological distress due to the fear of recurrence. This proposition is made given the positive outcome of an informational self-management intervention among patients undergoing radiotherapy to control illness uncertainty, and subsequently, to

reduce psychological distress after treatment (Stiegelis *et al.* 2004). A similar intervention may improve quality of life in cancer survivors and their family members living with feelings of illness uncertainty.

Furthermore, a nursing follow-up that involves families at risk of experiencing a second recurrence may be useful in helping them managing intense fear of recurrence. This is proposed because the data show that the patients with pancreatic cancer and ovarian cancer interviewed were experiencing high levels of anxiety and distress due to the momentous meaning they attributed to their type of cancer. This may be because the risk of recurrent cancer is significantly high among patients with pancreatic and ovarian cancer (Rose 2003, Wilkowski *et al.* 2006). Given that the findings of the current study are consistent with other research on the prevalence of psychological distress among cancer patients with different diagnoses (Zabora *et al.* 2001), screening for psychological distress appears appropriate among patients at high-risk of recurring in order to provide early supportive intervention if necessary. In addition, there is evidence supporting the idea that guidance surveillance after cancer therapy reduces rates of cancer-related worries and mortality (Lash *et al.* 2005).

An important feature in cancer care lies in multidisciplinary work. Effectiveness in cancer services requires professionals working together and that each of them knows their role within the oncology team. Nurses, as part of the oncology team, should be familiar with their roles, notably in the domain of psychosocial care. It is important that nurses assess individuals with moderate and high levels of distress so they can help them receive the best psychosocial care by liaising with other professionals. Referral to psycho-oncology, mental health, and/or pastoral services, as appropriate, is crucial in supportive cancer care.

I suggest an alternative approach that would consist of working in collaboration with informal social support, such as cancer self-help groups, which have been found to play a vital role in giving emotional help to cancer patients and survivors (Zabalegui *et al.* 2005). For example, self-help groups may support survivors and their families to cope better with the psychosocial issues of cancer by providing advice and

preventing perceptions of uncertainty (Wonghongkul *et al.* 2000), and helping families deal with the “sword of Damocles” (Muzzin *et al.* 1994). The development of combined work between health care services and social services may be particularly important in Spain where support groups and other supportive services are scarce (Reuben 2004a). To my knowledge, support groups only exist for breast, paediatric, and laryngeal cancers. It is suggested that referral to support groups, or information about the existence of such groups, would be beneficial for Spanish families who may need different sources of support during the cancer trajectory.

In addition to the above proposal of implementation of a nursing follow-up that may be useful to reduce latent demoralisation of patients and family members during survivorship, I suggest assessing the family impact of recurrence in an attempt to recognise active demoralisation of patients and family members after diagnosis of recurrence and plan effective interventions to work with families.

LOOKING FOR THE WHOLE: ASSESSMENT OF THE IMPACT OF RECURRENCE ON THE FAMILY

Assessment is the basis of any form of nursing to obtain data on which to base appropriate interventions. The purpose of this section is to explore issues related to assessment of the impact of recurrence on the family and its importance and applicability in cancer practice.

PLACING RECURRENCE WITHIN THE FAMILY CONTEXT

Based on the three strands of family nursing assessment -structural, developmental, and functional- (Whyte & Donaldson 1999, Wright & Leahey 1993), this section provides a basic direction to explore family relationships, illness trajectory, and pattern of communication in families facing a recurrence of cancer.

Exploring family structure and relationships

Toward the goal of developing an understanding of how members of a family experience recurrence, nurses need to know its organisation and functioning, particularly as it relates to the family's structure and roles. Assessment of relationships within the family will facilitate an understanding of the interaction between its members and at the same time, recognition of areas of strength and limitation in dealing with recurrent cancer. Family nursing has been paying more and more attention to the use of genograms as a tool to identify family relationships. I believe the use of this tool can be valuable in cancer nursing care in order to record information about family members and their relationships. For example, nurses can use genograms to highlight previous cancer cases in the family history, family members who accompany the patient at hospital, and age and gender of the members, as I have used in this research to gather data of the families (Appendix 3). The information collected will provide nurses with a quick overview of the family structure, health problem, and potential sources of support for the family. In addition, a nurse can make good use of the time during which s/he is requesting information about the family to observe patterns of communication in the families.

Although genograms may initially appear time-consuming and complex, the advantages may outweigh the extra time. First, the information gathered will be of value in the subsequent nursing process, as it will provide data to formulate a nursing diagnosis and to plan nursing interventions (Hanson *et al.* 2005). Second, rapport with the family may be facilitated so the involvement of the family with the nurse can be used to develop a healing environment during treatment for recurrent cancer. In other words, the establishment of a meaningful relationship with the family is an essential step in addressing the emotional impact on the family. When patients and family members develop a trusting relationship with a nurse, they may be more likely to share their experiences and to be open to nursing support (Mok & Chiu 2004). Thus, the use of genograms can be important in cancer care both as an

instrument to collect family data and a channel to initiate a therapeutic relationship with families.

Exploring the family's cancer trajectory and the family developmental phase

Understanding the dynamics of the family is important in recognising areas of strength and limitation in dealing with suffering during recurrence. Equally important is knowledge of the family's previous experience with cancer and healthcare. In this study, it has been found that when the nurses already knew the families, they reported that this was useful in the development of a therapeutic relationship with the family. In contrast, nurses reported care of unfamiliar patients to be more challenging, as they needed more time to identify patients' needs. When a patient is admitted to a cancer unit, information about his/her diagnosis and treatment is usually provided in medical records. Therefore, when the nurse and patient meet, a great amount of information is already available regarding the patient's medical characteristics. In addition to this information, the nurse should explore the *individual experience* to fully understand the experience of recurrence for cancer patients and their relatives.

For nurses to engage in a supportive relationship, a basic step is consideration of the past experience of the family with cancer. This study has shown that a past experience with cancer influenced the family's present experience with recurrence. It is essential that nurses acknowledge past experiences of patients and relatives with cancer, fear of recurrence and time since last diagnosis of cancer. If considering, for example, a nurse who is unfamiliar with the past experiences of a patient who had had severe side effects that threatened his/her life, the nurse may not expect the patient to be extremely distressed by the new treatment regime. As a result, s/he may not plan education about the difference between treatments, and s/he may not provide relief from the burden the patient is feeling because of anticipation of past experiences of treatment.

The diagnosis of recurrence affected families differently according to the developmental stage of the family. The data have shown that families reacted differently to recurrence depending on the family's position in the psychosocial life cycle, also noted in other research (Mahon 1991). For example, for young families (see families 3, 5, 7 and 15) dealing with recurrence might be a greater challenge because of the fear of leaving young children who needed the care of their parents to survive. At the same time, being a parent with young children brought great strength to continue the battle of cancer, as evidenced in chapter 6. A recurrence in middle age families (see families 1, 2, and 9) posed different challenges. Adolescent children were potentially more mature and they understood what was happening. During the interviews with parents, I observed that children might be excluded from events to prevent them from suffering. They actually might experience great distress because of a conspiracy of silence in their family but they often avoided making their anxiety and worries known. Consistent with other research (Issel *et al.* 1990), adolescents often used coping strategies including avoiding talking about the illness of their ill parent, maintaining normality, and spending time with the members of their family (reported by the daughter in Family 1 and Family 2). In addition to the conspiracy of silence that often leads to more suffering in the families, the fear of premature abandonment of the spouse and children has been shown. In older families with adult children (see families 4, 8, 10, 11, 12, and 13), preoccupations were based on the fear of abandonment of the spouse, and in particular about dependence on spouse and children.

Nurses should be aware of the patients' feelings about recurrence and how the relationship of these feelings affects their family members. However, very often nurses focus their attention on the patients alone, "forgetting" the family members. This lack of family system approach might prevent the nurses from fully understanding how the families managed recurrence. An evaluation of the family's circumstances might have a greater impact if the nurses explored the influence that each family member has on the perceptions of the illness. Although the approach of family nursing would appear favourable across all settings, I acknowledge the

challenge of conducting family nursing when there is limited time to intervene, for example during ambulatory hospitalisation.

Exploring family functioning and patterns of communication

Conspiracy of silence has been found a key element in the experience of recurrence in the Spanish families interviewed. A conspiracy of silence, consisting of hesitation about disclosure of cancer recurrence within the family and society, and avoiding discussion about cancer and feelings openly, might develop within the family seeking to show the best face of cancer. Some members of the family might be more distressed than others, an emotion that they might conceal to their relatives. This approach, initially attempting to reduce suffering, prevented expressions of feelings and created a milieu that lacked communication. This situation has been reported similarly in Spain where “even family members and friends may refer to the patient’s *problem* to avoid saying the word *cancer*” (Reuben 2004a, p. 32). The absence of expression of fears within the family may entail the emotional isolation of its members and intense suffering, especially in young and adolescent children. Consistent with this comment, Nelson and colleagues found that children who had a parent with cancer and were unable to discuss the illness with their parents showed high levels of anxiety (Nelson *et al.* 1994). It is important for nurses to take an active approach toward preventing families from suffering in isolation. I would argue that children may need to take a dynamic part in the experience of recurrence, so they can anticipate and prepare for what their parent is experiencing. When parents show difficulty in discussing their illness with their children, nurses as mediators may have an important role in organising effective communication among the members of a family.

A way nurses can obtain valuable information to better understand the family’s situation is assessment of the impact of recurrence on the family, and recognition of the family’s reality. In addition, nurses should ask questions of family members about their perceptions of the illness trajectory. The findings of this research show

that many families avoided bringing up sensitive topics when other family members were present. That was the reason I conducted the interviews with patients separately from the family members, except when the family reported its wishes to conduct the interview together. Considering my experience with families, I recommend nurses explore families' patterns of communications early in the nurse-family relationship and ask its members whether they prefer to conduct group or individual assessment. Observation of nonverbal communication, such as postures and attitudes, may produce significant information about the dynamics in families. Questioning should be also a strategy used by nurses to explore the family's pattern of communication. The important information gathered during this initial encounter will permit nurses to have greater knowledge of the family and will help detect the problem of a conspiracy of silence in the family. In addition, this encounter will create the opportunity to develop a healing atmosphere that may promote individuals' expression of feelings. When appropriate, the nurse can also use psychological instruments to complement information on the family's emotional health (different tools used most often for depression and anxiety assessment in cancer patients have been explored in chapter 2).

ENTERING THE OTHERS' WORLD: WHY IS IT IMPORTANT TO LOOK INTO FAMILY MEMBERS' EXPERIENCES?

This category provides two main arguments for the importance of exploring family members' experiences of recurrence and a discussion about the difficulty of meeting the family members' needs in clinical practice.

A first argument is that while a *cancer diagnosis* is common for all families, a *cancer experience* is unique. In other words, the understanding of the individual perceptions of cancer will help nurses avoid making inaccurate generalisations based on a cancer diagnosis. Accordingly, nurses can plan the most effective interventions with families to help them adapt to their experience of cancer.

A second argument in the importance of looking at family members' experiences relates to compassion and ethics. This research has found that family members, particularly spouses, might show significantly more fear of recurrence than the patients themselves, also highlighted in other research (Matthews 2003, Mellon *et al.* 2006). Furthermore, the current study has found that the impact of recurrence was equal to or even more devastating for family members than it was for the patients. This may be because family members are more worried about the future than the cancer patients themselves (Blanchard *et al.* 1997). There is evidence suggesting that although family members cannot share the physical aspect of recurrence, they do indeed suffer from its psychological ramifications. Therefore, the suffering of the family members of a cancer patient should be equally important for nursing, especially because support from family members is beneficial for cancer patients (Pistrang & Barker 1998), and it may reduce psychological distress in couples (Baider *et al.* 2003). In this regard, the practice of family nursing can enhance opportunities for discussion that may allow family members to express not only concerns related to their relative with cancer, but also opportunities to express their own feelings and concerns.

Hospitalisation may be a good time for relatives to talk with professionals. However, the therapeutic relationship between nurses and family members has been found limited. Family members usually asked about the condition of their ill relative. Besides, the nurses did not frequently initiate a supportive relationship with family members, although they recognised this to be important. A basic approach may be to invite family members to talk about their experiences, promoting expressions of feelings and concerns, as this study aimed to do. This attempt at communication may give nurses the opportunity to identify central needs for families living with a recurrence, which will help them to develop appropriate supportive interventions. For example, the issue of death was a main concern for family members in this study. Inviting relatives to express their awareness of death may enlighten and empower them to regain mastery over recurrence. Opening discussion of the fear of death can help the family to communicate their awareness of the future more directly. Moreover, the data reveal that communication with children about cancer is often

evaded (see families 1 and 3). When children are young and adolescent, discussion about their parent's illness may help them to cope better with the situation (Mahon 1991). Clarification of children's thoughts about their parent's condition may prevent misunderstanding of the illness prognosis, and subsequently reduce high levels of uncertainty. Further, an invitation to ask questions and encouraging ventilation of feelings, provided children are ready to do so, may enable them to describe their difficult experiences with cancer.

Assessment of the whole family with recurrence is however difficult in hospital. The rhythm of nursing work in hospital today clearly prevents this integrative approach which is also limited by the lack of family nurse specialists based in hospitals. Besides, the complexity of bringing together all family members in the hospital impedes effective assessment of the whole family, together with a lack of nursing diagnoses that take the whole family into consideration (Hanson & Boyd 1996). However, it is important to promote a family nursing role in cancer services because, as shown in this study, cancer causes distress and suffering in the family unit. Assessment of families' concerns will help nurses to support families to adapt to cancer, notably at the recurrent phase, as the information collected will serve as the foundation for the development of the most appropriate interventions for the members of the family. Besides, sensitive assessment of the family will help nurses to work in collaboration with the oncology team by referring the family, or one or several of its members, to the appropriate member of the team when necessary. A critical review of a selection of relevant studies has shown that the practice of family nursing can assist families adapt to the suffering of cancer (Flanagan 2001). Akin to Flanagan's suggestion that family nursing is a clinically effective approach to the care of families facing cancer, I suggest that family nursing interventions may have positive outcomes for families when a member has a recurrence of cancer.

EMOTIONAL ASSESSMENT OF THE FAMILY: WHO SHOULD BE INVOLVED?

Very often, professionals do not adequately address the emotional needs of patients and relatives during a cancer recurrence (Ferrell *et al.* 2003). This may be because practitioners lack information about who should carry out such emotional

assessment. The multidisciplinary team includes professionals from oncology, nursing, psychology, psychiatry, and other social health branches. Each professional has a specific role in seeking to achieve an integrative treatment plan which will contribute to the quality of cancer care. Oncologists treat physical and emotional aspects of cancer recurrence from the perspective of medicine. Cancer specialist nurses address physical and emotional concerns of patients and family members from the viewpoint of nursing. Psychologists are part of the oncology team because they address the psychological needs of individuals from the perspective of psychology. Psychiatrists deal with the psychopathology problems of patients and family members from the background of psychiatry. Therefore, the multidisciplinary team is the strength of healthcare services when work is coordinated and harmonious, and when its aim is to provide holistic care to the cancer patient and his/her family. However, this harmony can be interrupted when professionals lack guidance about who should do what and when. The *who* refers to the health carer who should fulfil a specific task. The *what* refers to the type of intervention that must be conducted to address the emotional impact of cancer. The *when* is concerned with the time that a specific role should be played to meet the needs of the patients and the family members. The discussion about the who, what, and when issues has not been resolved, and may never be, but what matters is that professionals from different disciplines perform their role adequately in order to achieve the best quality of care in cancer services.

A four-level model of professional psychological assessment and intervention has been developed by the National Institute for Clinical Excellence to improve supportive and palliative care for adults with cancer (NICE 2004). Level 1 consists of recognition of psychological distress at a general level. Health and social care professionals who are directly in charge of cancer patients undertake this assessment. Level 2 entails additional expertise to screen for psychological distress. Assessment has to be conducted by appropriately trained professionals, such as nurse specialists and general practitioners. Level 3 refers to assessment for psychological distress and diagnosis of some psychopathology. Trained and accredited professionals such as counsellors deliver intervention. Level 4 involves the assessment, diagnosis, and

interventions of psychological disorders which are carried out by mental health specialists. In contrast to levels 1 and 2 which can be delivered by general care professionals, 3 and 4 levels involve trained specialists to manage mild-moderate distress (level 3) and complex distress and severe affective disorders (level 4). In agreement with NICE's manual, I extend the view of individual assessment toward family assessment, and recommend that psychological assessment of the needs of the family facing a recurrence be studied in order to develop guidance for assessment at different levels and performed by different nurse roles.

There is evidence that demoralisation is frequent across different medical settings (Fava *et al.* 2001). Indeed, recent research has found demoralisation to be common in patients with a variety of medical conditions, such as gastrointestinal disorders, cardiovascular illness, endocrine disorders, and cancer (Mangelli *et al.* 2005). These findings suggest that health professionals in cancer services should be aware of the characteristics of demoralisation. Phrases including "this is too long" and "I feel tired" may be helpful to recognise signs of demoralisation, as the patients and relatives in this study repeatedly used them. However, nurses and oncologists should be also aware of the dynamic process of demoralisation. As supported in this study, demoralisation is not just a psychopathologic state but it is also an emotional response of individuals to the recurrent suffering that requires ongoing adaptation. The speed of adaptation differs though among individuals. Some may understand the situation quickly whereas others might need more time and can waver between hope and demoralisation. Understanding the common responses of families to cancer recurrence, and their psychosocial processes in adapting to the new crisis, is a first step in recognising emotional suffering of families experiencing recurrence. Although deciphering demoralisation will not be easy, neither is any type of emotional suffering (Butow *et al.* 2002), the next step will be to plan effective psychosocial interventions.

WORKING WITH FAMILIES TO MANAGE DEMORALISATION

Care for families experiencing recurrence cannot be reduced to simply identifying the emotional impact experienced by individual family members, and the family as a whole. Interventions to help families deal with demoralisation must be taken into account. This study has shown that patients and families perceived and experienced recurrence as a distressing time. It is then important for healthcare professionals to spend time reflecting on individuals' experiences, listening to them, and trying to understand how cancer recurrence and its treatment affect the everyday lives of families. A holistic approach in caring for cancer patients and their relatives at the recurrent phase should consider management of demoralisation. At present there are no studies exploring what type of drug is effective to manage demoralisation (Mangelli *et al.* 2005). However, psychotherapy is reported to be useful (Frank 1974, Frank & Frank 1991). Further, Angelino and Treisman (2001) have considered counselling valuable as an early approach to demoralisation in cancer patients:

Demoralisation arising out of a life circumstance, such as having cancer and all of the attendant fear and suffering, may respond well to a relatively unstructured supportive interaction with a caring provider. In general, therapeutic optimism, such as stressing the non-zero survival rates when informing patients of the diagnosis, along with a supportive, caring provider-patient relationship, goes far in helping patients deal appropriately with illness. Demoralisation responds well to regular contact with a provider, gentle reminders to maintain hope and count blessings, and knowledge that someone is listening and trying to help alleviate suffering (Angelino & Treisman, p. 348).

According to these authors, support and active listening from professionals is therapeutic in managing demoralisation. Following the suggestion by Angelino and Treisman, a supportive framework based on a therapeutic relationship that promotes hope and active listening would appear to be valuable to help understanding the experience of demoralisation among patients with recurrent cancer and their family members. A starting point would be the recognition that individuals may experience demoralisation, as I have discussed in detail in the above section. Nursing staff will

need to work with families in order to develop supportive approaches that help individuals adapt to the repeated crises of cancer. Here, it is important to look for the individual's inner sources of strength and the strength of the family unit itself to try to identify what means of dealing with adversity have worked in the past and will probably work again.

In an attempt to help families deal with the experience of demoralisation, the next two subcategories entitled *promoting supportive communication and adopting a strength-based approach* describe nursing approaches based on the findings of previous chapters for working with family strengths and resources.

PROMOTING SUPPORTIVE COMMUNICATION

I define supportive communication as any form of verbal interaction for the purpose of support, and in which the nurse aims to share communication with the patients and their relatives to help them acquire the necessary strength to deal with suffering.

This study has only included patients who were informed of their diagnosis. Yet, the findings highlight a conspiracy of silence from both patients and family members. On occasion, the nurses co-operated with relatives to hide the patient's prognosis which the family members did not want to openly express to their loved ones. This occurred when family members asked professionals to conceal prognoses from patients. An Australian group of researchers have reported in their study of 130 patients newly diagnosed with melanoma that giving the patient as much information as needed, and talking about the patient's feelings and prognosis are among other practices which may reduce anxiety and depression in cancer patients (Schofield *et al.* 2003). Another study exploring interpersonal relationships in the community corroborated that open and honest communication helped patients to deal positively with their illness (McCann & Baker 2001). These findings suggest that the type of disclosure about issues related to diagnosis and prognosis of recurrence may be influential in the patients' psychological wellbeing. Based on these findings,

recommendations that divulge individually tailored information for those patients and family members desiring it and promote the development of counsellor nurses who facilitate open communication within families should be considered.

Besides giving information, it is more important that professionals inform realistically. While some patients may move again into remission and survivorship after treatment for recurrent cancer, this may be impossible for others. In these cases, palliative care can maintain quality of life for patients and their family members by providing supportive and truthful communication (Fallowfield *et al.* 2002).

ADOPTING A STRENGTH-BASED APPROACH

A strength-based approach, distinctive of the McGill Model of Nursing, is characterised by a focus on the individual's and family's strengths and resources (Feeley & Gottlieb 2000). That is, a strength-based approach to work with families relates to a shift of approach from one that focuses on disease and pain to one that focuses on human and social potential (Blundo & McDaniel 2004). The strengths perspective has been defined as:

A collaborative and respectful belief in the complexity of "illnesses and trauma" in terms of the biological, psychological, social, cultural, and spiritual life and the unique personal histories of an individual and his or her family and community (Blundo & McDaniel 2004, p. 52)

The category of rebuilding morale described in chapter 6, involves three main sources of strength to be regarded as essential for families to cope with challenges during recurrence. These were family strength that consisted of reciprocal support between patients and family members, personal strength including characteristics, beliefs, and abilities that reside within the individual, and nursing support. I will use this model combined with the emerged categories to reflect feasible nursing approaches for helping families during cancer recurrence.

The first step is the recognition of strengths by both the nurses and the family (Feeley & Gottlieb 2000). The simplest way to obtain information on support and strengths is to ask families to describe their strengths and the support in their lives. Nurses can identify the family strengths when listening to them tell their stories and concerns, as I did when I listened to the patients and family members talk about their experiences of facing cancer again. Exploration of individual's and family's strengths can be also done by inquiring about how families have coped with prior difficult events. In this study, I asked the families about how they had managed previous cancer and how they were managing the current situation. Once individual and family strengths have been identified, nurses can use the identified strengths to work with families in order to help them adapt to the situation.

The family has been found to be a key element in rebuilding morale and continuing the battle against cancer. Therefore, maintaining the family function should be a priority for enhancing supportive care. For instance, nurses can use a strength-based approach to help spouses recognise that feelings of exhaustion and fear are normal reactions to the hardship of recurrence.

Furthermore, nurses should help families find and construct meaning that give them a sense of purpose, mastery, and acceptance of the cancer situation. Viktor Frankl, Austrian psychiatrist and a holocaust survivor who wrote about his suffering in concentration camps, came to the conclusion that even in the most painful and dehumanised circumstances, life has meaning and suffering is meaningful:

The meaning is always there, like barns full of valuable experiences. It may be the deeds we have done, or the things we have learned, the love we have had for someone else, or the suffering we have overcome with courage and resolution. Each of these brings meaning to life. Indeed, to bear a terrible fate with dignity is something extraordinary. To master your fate and use your suffering to help others is for me the height of all meaning (Cited in Mahoney 1997, p. 32)

This philosophy of suffering was the basic foundation of Frankl's later existential psychoanalysis, known as logotherapy (Frankl 1991). In this study, spirituality

covering religious attitudes and existential dimensions has been found useful for some patients and families to rebuild morale. For example, religion gave comfort and strength to families who had faith in God in times of adversity. Existential dimensions related to the belief in fate gave some of the patients meaning to life. Others also found that patients with recurrent cancer look to faith for hope (Ballard *et al.* 1997). Using this understanding, nurses can help families maintaining hope by using individuals' existing beliefs. Personal growth, gained through the experience of living with cancer, has been also reported by the families to be invaluable in dealing with recurrence. It helped some families to understand suffering and it encompassed the search for purpose, serenity, and optimism. Therefore, nurses will need to understand the type of support the patients and their relatives are searching for.

At every stage of the work with a family experiencing recurrence, the nurses should consider how individual and family strengths may be used to solve a problem or deal with suffering. In addition to this, resources such as support from professionals may help families decide the best way to handle difficulties during recurrence. Particularly, a caring nursing relationship may be the cornerstone of supportive care for families.

An emerging understanding of the support given by nurses was the characteristic of supportive care through a caring approach. The care of families living with recurrence meant the nurse and the family entered into a supportive relationship characterised by a complex process that started by "knowing the patient" (described in chapter 4). Emotional supportive relationships appear to depend on the nature of the interpersonal encounter between families and nurses. This involved nurses familiarising themselves with the experiences of families in order to be able to work collaboratively with them. These findings are consistent with other research in palliative care (Skilbeck & Payne 2003).

One of the most effective support tools that nurses expressed was the use of active listening. Active listening, however, is not as simple as it appears. It requires time, an empathetic attitude, and willingness to help. Listening to the psychosocial concerns that the families experience during cancer recurrence is thought to be twice helpful.

First, it will give families the chance to express concerns that may not be shared within the family because of fear of adding suffering to the situation. Second, it will help nurses gain a better understanding of the psychosocial concerns of the families.

As noted earlier, it is crucial for the multidisciplinary team to be involved in providing supportive cancer care; referrals should be also made to appropriate specialists when necessary.

When patients continue to suffer from demoralisation despite best efforts, referral to a psychotherapist is indicated (Angelino & Treisman, p. 348).

Protocols for coordinating referrals need to develop and/or improve in order to meet the psychosocial needs of families showing intense demoralisation, which prevents them from dealing with the situation. Yet, the reality is that nurses often lack psychosocial training, limiting their provision of effective psychosocial care. Therefore, it is important that training on psychosocial issues in cancer be improved or put in place, as appropriate, in primary cancer services and hospitals.

MEETING NURSES' CHALLENGES IN EFFECTIVE CANCER CARE

Any successful therapy is based on knowledge of specific theoretical concepts and competency. The clinical reality is that many nurses are trained from a physical-oriented perspective and lack the background needed to assess and care for psychosocial-oriented problems, as the data in this study show. This may be the reason why the nurses focused more on the physical aspects of cancer care, an observation also mentioned in a study exploring the views of families, physicians and nurses about end-of-life care (Steinhauser *et al.* 2000). Indeed, the interviewed nurses agreed that physical care was offered systematically in contrast to emotional care that was “harder”, partly because many nurses had little, if any, training in psycho-oncology, and then they “did their best” in providing emotional support based on warmth and sympathy. Yet this does not compensate for lack of supportive

care based on designed intervention. Therefore, the findings of this study suggest a need for strengthening psychosocial care training for cancer nursing, mostly because supportive care must address the totality of the individual, and this includes the physical, psychological, social, and spiritual dimensions (NICE 2004).

DEVELOPMENT OF EDUCATION PROGRAMS FOR CANCER NURSES

Many nurses reported not knowing how to talk about and answer patients' emotional concerns and feelings, resulting in distancing from patients. Literature on nurse-patient communication has also found that hospice nurses often use blocking behaviours, notably when patients disclose their feelings (Booth *et al.* 1996). Similarly, Wilkinson (1991) found an overall poor level of facilitative communication in nurse-cancer patient interaction. Further, Wilkinson's findings indicated that blocking behaviours were most evident with patients with a recurrence of the disease, resulting in more than 50% of the nurses avoiding talking about patients' worries (Wilkinson 1991).

In emphasising the importance of creating a healing environment for the care of families suffering with recurrence, most critical attention should be given to the area of nursing communication. Communication involves more than the process of informing; it also involves transmitting emotions, recognising these emotions, and letting the patients know that their emotions have been recognised (Sheppard 1993). Good communication is a basic component of quality cancer practice (DoH 2000), yet healthcare professionals do not always communicate well with patients due to lack of communication skills (Butow 2001, Kruijver *et al.* 2001). Lack of expertise has negative effects on patients who may have more difficulty expressing their worries and suffering (Booth *et al.* 1996). On the contrary, studies have found a significant positive impact on the patient's emotional wellbeing when practitioners facilitate communication about informational and emotional cues (Fallowfield *et al.* 1990, Liu 2005, McCabe 2004). Likewise, this lack of expertise has a negative effect on healthcare professionals who may experience burnout due to deficient confidence

in communicating with patients (Isikhan *et al.* 2004, Tattersal *et al.* 1999, Ullrich & Fitzgerald 1990). In agreement with the literature, the results from this research suggest that communication is important in the therapeutic nursing relationship with families. Therefore, commitment should be addressed toward improving communication skills training for health care professionals working with cancer patients and their families, especially because a Cochrane review on this matter concludes that such programmes seem to be effective in improving some areas of cancer care professionals' communication skills (Fellowes *et al.* 2004). In addition to communication programmes, continued education about how to deal with patients with recurrent cancer and terminal disease, and their families, should be a priority in cancer nursing. This is because caring for these families during the recurrent and terminal phases of cancer appears very distressing for nurses (Dunniece & Slevin 2000, McHugh *et al.* 2003). Finally, education programmes about how to deal with issues of death (Mok *et al.* 2002, Sherman *et al.* 2005), loss and grief (Matzo *et al.* 2003, Sherman *et al.* 2003), suffering (Lindholm & Eriksson 1993), families living with cancer (Chesla 2005), and emotional labour in general (McQueen 2004) should be a priority in cancer nursing.

SUPPORT FOR CANCER NURSES

The experience of recurrence touches the patients and their family members profoundly, and it is evident from this study that for the nurses interviewed the experiences were also deep and profound. The category of "social suffering: the contagion of emotions" that emerged from the data of the nurses when meeting families they already knew after a diagnosis of recurrence, emphasises that the caring aspects of a nurse's role can be difficult, as other research has also mentioned (Bolton 2000). Some authors have used the term "compathy" to refer to the distress response of nurses when being confronted with patients' and families' suffering (Morse & Mitcham 1997a). There is evidence that nursing staff working in oncology can experience great stress and burnout (Escot *et al.* 2001, Sherman 2004).

Therefore, the findings of this study and the literature suggest recommendations for supporting nurses in managing their own distress.

Clinical discussion sessions can provide cancer nurses with the opportunity to learn strategies for acquiring strength to face recurrence. The sessions may consist of discussing what recurrence involves for them at both personal and professional levels. These sessions may provide a forum to further elaborate and refine the operationalisation of working with families. Through the discussion of experiences and the sharing of emotions with colleagues, nurses may feel supported in managing the potential “psychological sequelae” of caring for families suffering cancer.

Summary

In an attempt to refute many authors’ idea that demoralisation is associated with lack of hope, loss of meaning, and even thoughts of suicide, this work provides a re-conceptualisation of demoralisation in the context of cancer recurrence, in addition to a theoretical foundation for family nursing in cancer care. In particular, this chapter has discussed how the innovative account of demoralisation in cancer recurrence can be used, against this tendency of “demoralisation associated with psychiatric morbidity”, to provide an understanding of demoralisation as an emotional response to a repeated threatening event, such as a recurrence of cancer. In this regard, demoralisation is seen as a continuity of past suffering due to primary cancer. Besides, by introducing the concepts of “latent demoralisation, “active demoralisation” and “residual demoralisation”, this theoretical proposal highlights how demoralisation changes throughout the experience of cancer recurrence. In particular, the theory proposes that frequent signs of demoralisation in cancer recurrence include fear, exhaustion, uncertainty, and awareness of death. Finally, the theoretical proposal highlights the potential value of this work for cancer care, especially for the practice of family nursing in cancer care. For example, the proposal can be used in cancer practice as a caring approach for those families diagnosed with

a recurrence of cancer, with the aim of improving family adaptation to recurrence. Besides, the proposal can serve as a preventive approach for those families identified as at risk of persistent demoralisation which may result in family dysfunction and difficulties in adapting to cancer recurrence.

In providing its own understanding of the phenomenon of cancer recurrence, the grounded theory presented articulates a preliminary nursing framework for the management of demoralisation in families experiencing recurrence of cancer. A substantive theory is proposed, a core category and main categories are identified, definitions are established, conditions modifying the experience of demoralisation are presented, and new perspectives for management of demoralisation are suggested. Assuredly, the theory may need to be further developed. Besides, the applicability of the interpretation I have formulated requires that readers make the basic adjustments to the personal and cultural circumstances of each family. This is because there is no one right way to care; each family experiences illness in a unique way that is shaped by culture, illness trajectory, beliefs, values, and experiences. Although there are common phases of cancer that involve specific challenges and nursing interventions, nurses still need to explore the individual experiences of families facing cancer recurrence.

CHAPTER 8

CONCLUSIONS AND RECOMMENDATIONS

Introduction

This grounded theory study had two general aims. The first aim consisted in providing understanding of the psychosocial impact of a recurrence of cancer. The second aim was to generate a substantive theory that described the experience of cancer recurrence from a psychosocial perspective. This study has reached these aims by revealing patients' and family members' experiences of cancer recurrence and nurses' experiences of caring for these families and by proposing a theory of demoralisation in cancer recurrence for family nursing.

This final chapter summarises the main findings of this study and discusses implications for policy and practice. Recommendations for future planning in research and education are also made.

Findings of the study

Discussion focuses here on the most relevant findings in relation to the psychosocial experience of cancer recurrence described in chapter 4, 5, and 6. The proposed substantive theory emerged from this study further leads to an understanding of how recurrence is conceptualised by patients, family members, and nurses, and how nurses can work with these families during a recurrence of cancer.

This study has revealed that the experience of recurrence was distressing for patients and their family members, as well as for nurses who cared for them. During survivorship, patients and their families feared that cancer might recur. This fear led

families to be on their guard and to fear medical follow-up which often was associated with the possibility of recurrence. When patients were informed that their cancer had come back, the fear became a reality for the patients and families who had to face the physical and psychosocial consequences of cancer again. In this context, suffering was the common response to the impact of recurrence. The term “again”, expressed by all the participants, symbolised a beginning and a continuation with cancer; it represented new suffering for the families and it implied a reencounter with health services. This study has thrown light on the fact that suffering in recurrence took on a social dimension in that it was not just an individual experience but also it was a family experience, as recurrence affected the patient and the rest of the family members who suffered with and for the patient. Also the social construction of suffering impacted on the nurses caring for the patients and their families. This occurred as a result of social interactionism, upon which grounded theory is based (Strauss & Corbin 1990). The social construction of suffering then could be experienced by the nurses observing and empathising with the suffering of the patients and family members in their care.

An important finding of this study concerns the nature of suffering after recurrence. The response to recurrence has been found to be in the form of demoralisation, which was identified by exhaustion, uncertainty, and fear of death. Exhaustion was caused by the accumulation of earlier experiences with cancer together with the experience of new treatment and threats. Exhaustion was therefore an expression of the suffering caused by a repeated and enduring experience with cancer. Uncertainty was also central in recurrence. Not knowing if treatment would be effective in bringing about a remission precipitated feelings of uncertainty about the future, especially because previous treatment was perceived to be unsuccessful, as cancer had come back. This perception of uncertainty led patients and family members to live the present and avoid making important plans for the future. Furthermore, a diagnosis of recurrence suggested the idea of death again. Fear of death emerged first when patients were diagnosed with primary cancer. However, the repeated diagnoses and successive treatments for cancer reawakened the fear of death, resulting in demoralisation in both patients and family members. The prominence of death as a topic of awareness

increased especially among those families who had experienced repeated recurrences in a short time. For many patients and family members, recurrence was more distressing than the shock of the first diagnosis of cancer. The exhaustion and uncertainty of the families and their revival of the fear of death posed great challenges for nurses who described caring for the group of patients with recurrent cancer to be harder than caring for newly diagnosed cancer patients.

Although patients and families might feel demoralised after diagnosis of recurrence, they found meaning in their experience of suffering. Findings have suggested three main approaches of the families toward regaining strength to continue the battle against cancer. The first approach highlighted the importance of the family as a source of strength. In the face of hardship, family reciprocity and mutual support helped the patient and his/her family members rebuild morale. In addition, perseverance was seen as a personal resource that helped patients and family members maintain strength throughout the experience of recurrence. Finally, the human side of nursing was noted to be important during recurrence. The majority of patients and their family members perceived human caring related to the nurses' personal qualities and professional attitudes to be supportive for the patients. However, nursing support for family members was almost nonexistent although nurses did recognise that family members had needs during the recurrent phase. This lack of nursing support was expressed by family members in general, and also by nurses. What families described as the human attitude of nurses was referred to by the nurses themselves as giving supportive care. Nurses found it central to give priority to psychological care when caring for patients with recurrent cancer because they thought patients experienced greater emotional needs in this phase of cancer compared to the time of first diagnosis.

Contribution to knowledge

This thesis has contributed to existing knowledge in nursing and psycho-oncology in a number of ways. It has provided evidence of the impact of cancer recurrence on the

family. It has also indicated why the experience of recurrence is distressing for patients and family members, and why the experience of caring in the recurrent phase of cancer is challenging for nurses.

Based on a constant comparative analysis distinctive of grounded theory, this study has developed new knowledge of the psychosocial impact of a recurrence of cancer. A new understanding of the concept of demoralisation has emerged from the data. Demoralisation in recurrence as a core category has been found to include three main categories identified as latent demoralisation, active demoralisation, and residual demoralisation. Latent demoralisation has been defined as a condition that is potential but not evident and is characterised by fear of recurrence. This condition is experienced during survival of cancer and may develop into an active state after a diagnosis of recurrent cancer. The active demoralisation has been defined as a present condition limited in duration and with an identified cause as is the knowledge of facing cancer again. This active state is characterised by exhaustion caused by periodic and distressing treatment, uncertainty, and reawakening of fear of death. Residual demoralisation has been characterised by uncertainty that is associated with lack of confidence in treatment and the fear of an unknown future. Considering the new understanding of demoralisation, this study puts forward the following definition of the concept:

Demoralisation is an emotional response of a person or group of people to a repeated threatening event. Frequent signs of demoralisation in cancer recurrence include fear, exhaustion, uncertainty, and awareness of death. Demoralisation as a result of cancer recurrence can be generally considered as a normal response to recurrent suffering.

This definition adds to literature that supports that the concept of demoralisation can be identified as a normal response to difficult life-situations (Angelino & Treisman 2001, Frank & Frank 1991, Schwartz 2005, Slavney 1999, Vivar *et al.* 2006c) and adds to the simplistic view of demoralisation as only related to psychopathology.

Finally, little research has been done on how to recognise demoralisation in cancer patients, and almost none on interventions for managing demoralisation. The theory proposed brings early direction for assessing, recognising, and managing demoralisation from a nursing perspective. This last contribution should be regarded as an initial exploration of demoralisation in recurrence. Nonetheless, it is important as it represents a first attempt to acknowledge the concept from a nursing perspective.

Implications and recommendations

In this section, I will draw out some implications for policy and practice, and will consider the personal implications that arise from conducting this thesis. In addition, recommendations for education and research will be discussed.

IMPLICATIONS FOR POLICY

Efforts to improve the quality of care in cancer services have been noted across Europe. Notably, different policy schedules have been made (Calman & Hine 1995, Departamento de Salud 2002, NICE 2004). The findings of this study have shown that the impact of recurrence has echoes throughout the family system, affecting all members and their relationships. This study has shown that family members also experienced increased suffering in relation to the patient's experience of recurrence. At times, relatives might even feel more distressed than the patient. This observation was highlighted by some nurses, and by the patients themselves. However, nurses reported care for family members of patients with recurrence was almost nonexistent, this point being in agreement with literature cited throughout this thesis. Literature goes further saying that family members are invisible to health services (Lloyd 2000).

The findings of this qualitative study would support a health service policy that would propose a focus on the development of quality cancer care for the family with cancer. It would appear important to develop policy and practice to ensure that patients with cancer and close family members receive the necessary support throughout the cancer trajectory. This would include supportive care during diagnosis and treatment, survivorship, recurrence, and the dying phase. This integrative model for family-based care will require action on a number of fronts. Specifically, it will require that cancer services move on from the existing medical model to a biopsychosocial model. It will also require services to enhance investment in educational programs for cancer health providers as an essential component of cancer service improvement. In addition, cancer services will need to develop important procedures for monitoring care for patients and family members, and ensuring that services have the resources for delivering family centred care.

IMPLICATIONS FOR PRACTICE

This study highlights a number of implications for nursing practice. Considering the impact of recurrence on the family, this study supports the implementation of family nursing for cancer care. As proposed in chapter 7, nurses need to “enter the others’ world” and “look into family members’ experiences”. More attention needs to be given to spouses of cancer patients and other close family members taking into account that they may experience intense distress during the cancer trajectory.

Findings also support the need to assess previous experiences of families with cancer. Only by understanding the individual experiences of cancer, is it possible to comprehend suffering in recurrence. Assessment of the family structure, cancer trajectory, family functioning, and patterns of communication would help nurses recognise families’ needs and sources of strengths, and plan effective cancer care.

This study has shown that families used a variety of approaches to deal with the emotional experience of recurrence, including family support, spirituality, and

personal resources. Accordingly, nurses and other health professionals need to be aware of such approaches and use them to help families deal with recurrence. It is also important that nurses put special emphasis on the delivery of emotional and spiritual support in addition to meeting the physical and information needs of patients and families facing recurrence.

Families in this study identified human caring as supportive and essential in nursing care. Patients and family members described good nursing care as a combination of professional standards, including management of treatment and physical problems, and personal qualities such as empathy, affection, interest in people, and a human approach. These findings suggest that “the human side of nursing care” represents a positive approach in the direction of delivering supportive care and enhances the quality of care of families with cancer. Such an approach should be maintained and developed.

PERSONAL IMPLICATIONS

This thesis, in addition to having implications for policy and practice, was seen as significant on a personal level. It has provided me with the opportunity to fully explore my own concerns, suffering, and frustrations. Conducting this research has constituted a fundamental part of an understanding of myself as a researcher and as a human being. The *doctoral trajectory* has helped me to grown up, both academically and personally.

RECOMMENDATIONS FOR RESEARCH

The qualitative approach of this research was seen as an appropriate paradigm for the exploration of patients’ and family members’ experiences of cancer recurrence and their views of nursing care. Grounded theory provided a helpful approach to capture the nature of suffering through interactive dialogue between the researcher and the

participants. In the inductive process of building a theory, this study has brought together different sources of data, including interviews with patients, family members and nurses, memos, and literature. The diversity of sources has allowed deep understanding of how individuals perceived a cancer recurrence and the accounts they gave of it. This research may be valuable to illustrate the importance of triangulation of sources of data as a strategy to capture the meaning of a social phenomenon from different perspectives.

However, this study has several limitations which need to be considered in future research. First, the interviews were conducted, on average, from one to 6 months after diagnosis of recurrence. The time of the interviews in relation to the point within the cancer trajectory might have influenced responses of the patients and family members. Views of recurrence might vary depending on the period of time after diagnosis of recurrence. However, lack of follow-up of families has prevented exploration of changes that could occur during remission and survival, or when facing death after recurrence. Therefore, longitudinal research is advised to trace the families' experiences throughout the recurrent phase of cancer and identify psychosocial changes within the cancer trajectory.

Second, the sample included patients experiencing recurrence of cancer, whether it was a first, second or more frequent recurrences. Future research can inform of differences between a first experience of recurrence and more recurrences. Besides, comparative studies need to be scheduled to evaluate the emotional impact of cancer recurrence on long-term cancer survivors versus short-term cancer survivors.

It would be also interesting to undertake a similar study comparing groups of patients in order to test the emerging theory. I propose to use two participant groups in which demoralisation can emerge as a result of recurrence of illness. This may include a sample of cardiac patients who have had a repeated heart attack and a sample of patients with recurrent cancer. Although these groups may have different needs, it is suggested that they may share experiences of demoralisation as a response to the recurrence of their illness. This is partly because both groups have experienced a former experience of distressing treatment such as heart transplantation in cardiac

patients, or marrow transplantation in cancer patients, and both may have feared death. This would increase understanding of patterns of demoralisation in individuals facing a repeated life-threatening event.

Further work as to how nursing care can help families manage cancer recurrence needs to be undertaken. Multi-method approaches including qualitative and quantitative studies seem to be significant to the development of this knowledge. Accordingly, nurses' understanding of the expectations of families regarding their nursing needs could be enhanced: this being a useful way forward in the development of quality family nursing in cancer services.

Finally, the following hypotheses derived from this study need to be tested in future research:

- ◆ Young families with a recurrence of cancer show more intense demoralisation compared to older families.
- ◆ Mutual support in the family decreases demoralisation.
- ◆ Physical decline of the patient with recurrent cancer increases demoralisation.

RECOMMENDATIONS FOR EDUCATION

This study has shown that the phase of recurrence is unique and that patients and family members had specific psychosocial needs during this phase of cancer. It is important that nurses have a conceptual framework within which to work, that would help them meet the specific needs of families experiencing recurrence of cancer. This is similar to other areas of oncology, such as palliative care, for which there are conceptual frameworks that provide direction for quality of care (NICE 2004). Further research needs to schedule studies that explore and develop nursing theories that provide foundations for the care of families with cancer.

This research also supports the need for further training for nurses in relation to communication skills and education in psycho-oncology. Education modules on supportive care, encompassing psychosocial issues at the different phases of the cancer trajectory, could be valuable to help nurses work with families.

Lastly, the findings of this study need to be circulated among the cancer nursing community and other professional groups who care for patients and families in the different phases of cancer. In particular, the concept of demoralisation that emerged from this study, and differs from some authors' conceptual understanding, needs to be presented in journal papers, conferences, and scientific meeting. Scientists and health care professionals must continue investigation into the characteristics of demoralisation in cancer. This is important because the concept has received little attention in research, and even most important because there are controversial definitions in the literature.

Summary

Findings from this study lend support to existing knowledge about the impact of cancer recurrence on the family, and nurses' experience of caring for families during the recurrent phase of cancer. In addition, new knowledge emerged from this thesis. A strength of this study is that it adds to the body of knowledge on the nature of suffering of patients and families when cancer comes back. Accordingly, this study provides nurses and other cancer health professionals with a new understanding of families' psychosocial experience of cancer recurrence.

The substantive theory of demoralisation proposed in this thesis provides an initial framework for family nursing for the assessment and management of the emotional response of patients and family members to cancer recurrence. This understanding is original since no cancer research has explored the concept from a nursing perspective. Further research is required to expand on the nature of suffering of families facing cancer again.

Finally, this thesis sheds light on the need to support the family members of patients with recurrent cancer. Together with existing literature, it provides strong evidence for the development of family nursing in cancer services. A well-planned effort is necessary to effectively meet the health care needs of families with cancer. To promote this, further attention must be paid to the family experience of cancer and to nurses' experiences of caring for patients and families throughout the different phases of the cancer trajectory.

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APPENDICES

1. Glossary of terms

Cancer recurrence

Clinical state in which a person with cancer who has successfully completed an initial course of therapy and has been without signs and symptoms of clinical disease for a period of at least 6 months is found to again have evidence of malignancy (Mahon & Casperson 1997). See definition of recurrent cancer.

Cancer survivor

Person who has survived to cancer after completion of cancer treatment programmes and who may experience physical, psychosocial, and spiritual sequelae due to side effects of treatments and impact of cancer. Survivors who have lived beyond five years without recurrence are frequently called long-term cancer survivors and short-term cancer survivors are generally survivors who have lived without evidence of the disease between end of treatment and to 5 years after a diagnosis of cancer.

Cancer survivorship

Is a distinctive phase of the cancer trajectory (Hewitt *et al* 2006). It is experienced by cancer survivors and their family members.

Demoralisation

Emotional reaction caused by a distressing event. In the context of this study, it is an emotional response to the suffering of a diagnosis of recurrent cancer. Frequent signs of demoralisation in recurrence include fear, exhaustion, uncertainty, and awareness of death.

Emotional care

Type of care provided to meet the emotional needs of people with cancer and their family members. It includes emotional support, counselling, and psychotherapies (Pujol 2003).

Emotional impact

Range of physical, behaviour, and emotional responses that a person shows when she is confronted to a situation that she perceived as threatening.

Family

Group of individuals that are interconnected by bonds of love, and have a role responsibility to each other. A family member is a person who is part of the family.

Family nursing practice

The delivery of care to families and family members in health and illness situations (Friedman *et al.* 2003, p. 651).

Grounded theory

Qualitative research that aims to develop a theory grounded in the collected data to explain a social phenomenon.

Multidisciplinary team

A group of health and social care professionals from a range of disciplines who meet regularly to discuss and agree plans of treatment and care for people with a particular type of cancer or problem, or in a particular location (NICE 2004, P.200).

Metastasis

Spread of cancer cells to others parts of the body. It includes regional metastases (cells that have spread closed to the site of the primary tumour) and distant metastases (cells that have spread to another part of the body from which the primary tumour grew).

Recurrent cancer

Cancer that has locally developed or has spread to a regional part of the body or metastasised to tissues farther away from where the first cancer was located (Touboul *et al* 1999). See definition of cancer recurrence.

Substantive theory

A theory designed to explain a specific area of a formal theory. In this work,

the emerged substantive theory explains the psychosocial phase of recurrent cancer.

Suffering

Distress experienced by individuals as a result of a distressing event, such as a recurrence of cancer.

Supportive care

Care that helps individuals with cancer and their families to deal with cancer and its treatment throughout the cancer trajectory.

Survival

Period of time from diagnosis of cancer to death.

2. Interview guides

INTERVIEW GUIDES: PATIENTS

(Translated from Spanish)

1ST INTERVIEW GUIDE

Impact of Cancer Recurrence

- Could you tell me the reason of your hospitalisation?
- How were you informed about your new diagnosis? (if it has not been mentioned previously)
- What changes have you experienced in your daily life after the diagnosis of relapse?
- How are you managing your illness?
- How has recurrence affected your family dynamics?
- Who in your family is more affected by this situation?
- What are your main fears and preoccupations at the moment?
- What are your future plans when you finish treatment?

Perceptions of Nursing Care

- Could you tell me what is your perception of the care provided by nurses during your stay?
- To what extent does nursing care help you cope with this situation?
- What type of nursing support would you like to receive during your stay?
- Have you perceived any change in nurses' attitudes regarding previous hospitalisations? Can you tell me about this?

▪

2ND INTERVIEW GUIDE *(new questions are in bold type)*

Impact of Cancer Recurrence

- Could you tell me how were you informed of your new diagnosis?
- **Did you have any symptomatology before you were diagnosed?**
- What changes have you experienced in your daily life after the diagnosis of relapse?
- **Have you enjoyed life during the periods between follow-ups? Could you tell me more about this?**
- How are you managing your illness?
- **Is there any difference between the first diagnosis of cancer and the current situation? What diagnosis do you think is more difficult to cope with?**
- **How are your family members managing this situation?**
- Who in your family is more affected by this situation? Why?
- What are your main fears and preoccupations at the moment?
- What are your future plans when you finish treatment?

Perceptions of Nursing Care

- **Could you tell me what type of nursing support are you receiving during your stay?**
- To what extent does nursing care help you cope with this situation?
- **What aspect of nursing care do you think is more important during your stay? Are you receiving it?**
- What type of nursing support would you like to receive during your stay?

▪

3RD INTERVIEW GUIDE *(new questions are in bold type)*

Impact of Cancer Recurrence

- Could you tell me how were you informed of your new diagnosis?
- **What is the meaning of this relapse for you?**
- What changes have you experienced in your daily life after the diagnosis of relapse?
- **Did you experience anxiety or fear before regular follow-ups? Why?**
- How are you managing your illness?
- Is there any difference between the first diagnosis of cancer and this time? What time do you think is more difficult to cope with?
- **Has the disease brought you anything?**
- How are your family members managing this situation?
- Who in your family is more affected by this situation? Why?
- What are your main fears and preoccupations at the moment?
- What are your future plans when you finish treatment?

Perceptions of Nursing Care

- Could you tell me what type of nursing support are you receiving during your stay?
- To what extent does nursing care help you cope with this situation?
- **Have you received enough information about treatment and its management?**
- **To what extent do you feel emotionally supported by nurses?**
- What aspect of nursing care do you think is more important during your stay? Are you receiving it?
- What type of nursing support would you like to receive from nurses?

▪

4TH INTERVIEW GUIDE *(new questions are in bold type)*

Impact of Cancer Recurrence

- Could you tell me how were you informed about your new diagnosis?
- What is the meaning of this relapse for you?
- What changes have you experienced in your daily life after the diagnosis of relapse?
- How are you managing your illness?
- **How have you used your previous experience with cancer to cope with the current situation?**
- Has the disease brought you anything?
- How are your family members managing this situation?
- What are your main fears and preoccupations at the moment?
- What are your future plans when you finish treatment?

Perceptions of Nursing Care

- Could you tell me what type of nursing support are you receiving during your stay?
- Have you received enough information about your treatment and its management?
- To what extent do you feel emotionally supported by nurses?
- To what extent does nursing care help you cope with this situation?
- What aspect of nursing care do you think is more important during your stay?
Are you receiving it?
- What type of nursing support would you like to receive during your stay?

▪

INTERVIEW GUIDES: FAMILY MEMBERS

(Translated from Spanish)

1ST INTERVIEW GUIDE

Impact of the Cancer Recurrence

- Could you tell me how were you informed of the diagnosis of relapse of your relative?
- What changes have you experienced in the family after this last diagnosis?
- How do you feel after passing through this situation again?
- What are your main fears and preoccupations at the moment?
- Could you tell me what aspect of your relative's illness is more difficult to cope with?
- Who in the family is more affected by this situation?

Perception of Nursing Care

- Could you tell me what is your perception of the care provided by nurses to your relative?
- What is your perception of the care provided by nurses to you, as a family member?
- Have you received any kind of nursing support that helps you cope with this situation?
- What type of nursing support would you like to receive during this stay?
- Have you perceived any change in nurses' attitudes regarding previous hospitalisations? Can you tell me about this?

▪

2ND INTERVIEW GUIDE *(new questions are in bold type)*

Impact of Cancer Recurrence

- Could you tell me how were you informed about the diagnosis of relapse of your relative?
- What changes have you experienced in the family after this last diagnosis?
- How do you feel after passing through this situation again?
- **Regarding how you are managing the situation, is there any difference between the first diagnosis of cancer and this diagnosis?**
- What are your main fears and/or preoccupations at the moment?
- Can you tell me what aspect of your relative's illness is more difficult to cope with?
- Who in the family is more affected by this situation?

Perception of Nursing Care

- Could you tell me what is your perception of the care provided by nurses to your relative?
- What is your perception of the care provided by nurses to you, as a family member?
- Have you received any kind of nursing support that helps you cope with this situation?
- **To what extent do you feel emotionally supported by nurses?**
- **What type of nursing support would you like to receive from nurses during your relative's stay?**

▪

3RD INTERVIEW GUIDE *(new questions are in bold type)*

Impact of Cancer Recurrence

- Could you tell me how were you informed about the diagnosis of relapse of your relative?
- **What is the meaning of this relapse for you?**
- What changes have you experienced in the family after this last diagnosis?
- How are you coping with your relative's illness?
- Regarding how you are managing the situation, is there any difference between the first diagnosis of cancer and this diagnosis?
- What are your main fears and preoccupations at the moment?
- Can you tell me what aspect of your relative's illness is more difficult to cope with?
- Who in the family is more affected by this situation?

Perception of Nursing Care

- Could you tell me what is your perception of the care provided by nurses to your relative?
- What is your perception of the care provided by nurses to you, as a family member?
- Have you received any kind of nursing support that helps you cope with this situation?
- To what extent do you feel emotionally supported by nurses?
- **In what sense the support provided by nurses helps you cope with this situation?**
- What type of nursing support would you like to receive from nurses during your relative's stay?

▪

4TH INTERVIEW GUIDE *(new questions are in bold type)*

Impact of Cancer Recurrence

- Could you tell me how were you informed about the diagnosis of relapse of your relative?
- What is the meaning of this illness for you?
- What changes have you experienced in the family after this last diagnosis?
- How are you coping with your relative's illness?
- **How do you use your previous experience with cancer to cope with the current situation?**
- What are your main fears and preoccupations at the moment?
- Can you tell me what aspect of your relative's illness is more difficult to cope with?

Perception of Nursing Care

- Could you tell me what is your perception of the care provided by nurses to your relative?
- What is your perception of the care provided by nurses to you, as a family member?
- Have you received any kind of nursing support that helps you cope with this situation?
- To what extent do you feel emotionally supported by nurses?
- In what sense the support provided by nurses helps you cope with this situation?
- What type of nursing support would you like to receive from nurses during your relative's stay?

▪

INTERVIEW GUIDES: NURSES

(Translated from Spanish)

1ST INTERVIEW GUIDE

Introductory question

- What is your experience of caring for patients diagnosed with a recurrence of cancer and their family members?

Nurses' Perception of Families' Needs

- Could you tell me what are the main fears and preoccupations of patients with recurrent cancer?
- Is there any difference between the first diagnosis of cancer and a diagnosis of recurrence?
- Some studies have documented that nurses do not always give priority to emotional care when caring for cancer patients. To what extent do you agree with this?
- Suffering from cancer is a family affair since the diagnosis creates emotional stress to both patients and their relatives. What do you think are the main fears and preoccupations of the family members of patients with recurrent cancer?
- How do you think nursing care could be improved for these families?

▪

2ND INTERVIEW GUIDE *(new questions are in bold type)*

Introductory question

- What is your experience of caring for patients diagnosed with a recurrence of cancer and their family members?

Nurses' Perception of Families' Needs

- Could you tell me what are the main fears and preoccupations of patients with recurrent cancer?
- Some studies have documented that nurses do not always give priority to emotional care when caring for cancer patients. To what extent do you agree with this?
- **Is there any difference in the way you care for newly diagnosed cancer patients and patients with recurrent cancer?**
- Suffering from cancer is a family affair since the diagnosis creates emotional stress to both patients and their relatives. What do you think are the main fears and preoccupations of the family members of patients with recurrent cancer?
- **Is there is any barrier to care for these patients and their family members?**
- How do you think nursing care could be improved for these families?

▪

3RD INTERVIEW GUIDE *(new questions are in bold type)*

Introductory questions

- What is your experience of caring for patients diagnosed with a recurrence of cancer and their family members?
- **What is the meaning of cancer recurrence for you?**

Nurses' Perception of Families' Needs

- Could you tell me what are the needs of patients with recurrent cancer?
- To what extent do you meet these needs?
- Some studies have documented that nurses do not always give priority to emotional care when caring for cancer patients. To what extent do you agree with this?
- **Some nurses have told me that caring for patients with cancer recurrence is harder. To what extent is this your perception?**
- Suffering from cancer is a family affair since the diagnosis creates emotional stress to both patients and their relatives. What do you think are the main needs of the family members of patients with recurrent cancer?
- How do you think nursing care could be improved for these families?

▪

4TH INTERVIEW GUIDE *(new questions are in bold type)*

Introductory questions

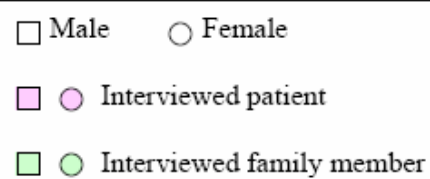
- What is your experience of caring for patients diagnosed with a recurrence of cancer and their family members?
- What is the meaning of cancer recurrence for you?

Nurses' Perception of Families' Needs

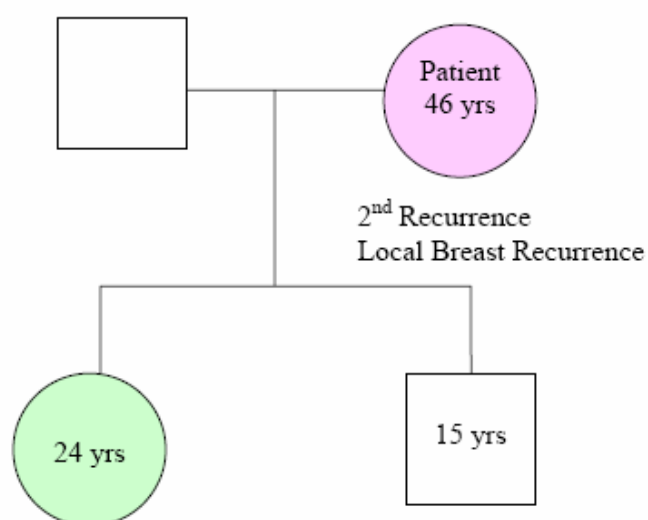
- Could you tell me what are the needs of patients with recurrent cancer?
- To what extent do you meet these needs?
- Some nurses have told me that caring for patients with cancer recurrence is harder. To what extent is this your perception?
- **Many nurses have mentioned that their main focus with patients with recurrence is on emotional aspects. To what extent is this your experience?**
- Suffering from cancer is a family affair since the diagnosis creates emotional stress to both patients and their relatives. What do you think are the main needs of the family members of patients with recurrent cancer?
- **To what extent do you meet the needs of family members?**
- How do you think nursing care could be improved for these families?

▪

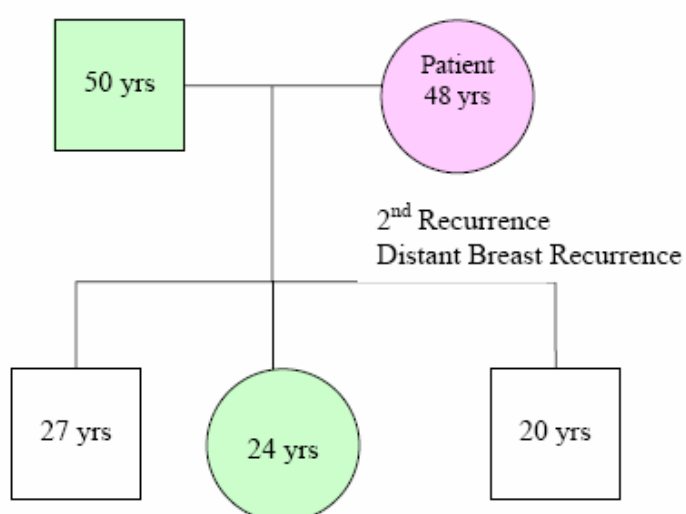
3. Family genograms



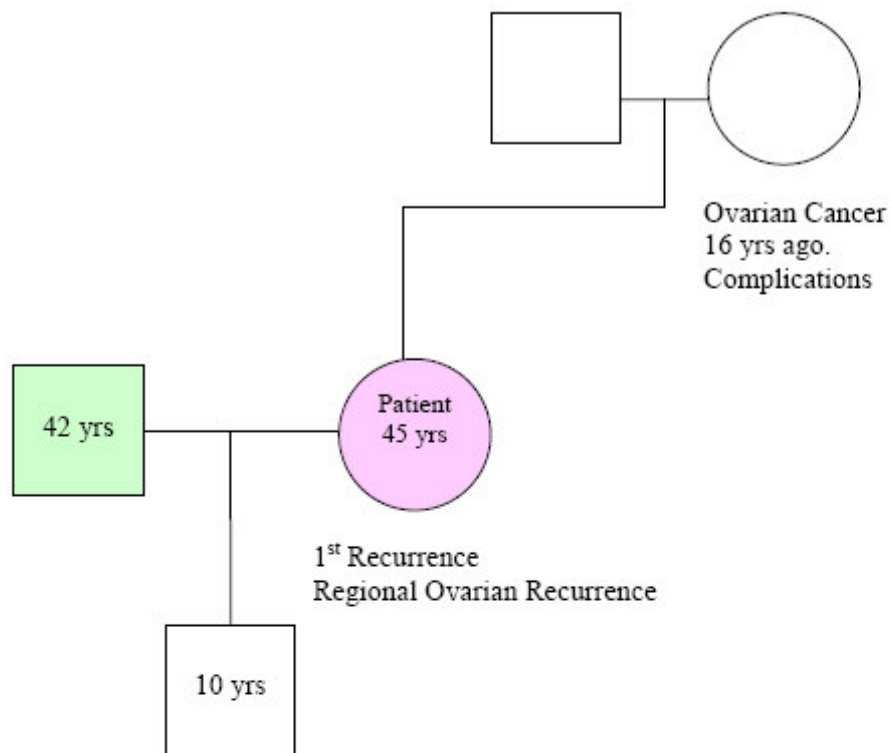
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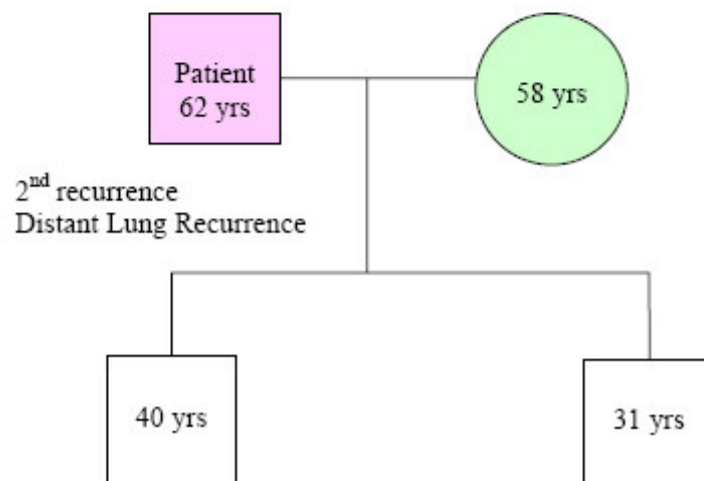
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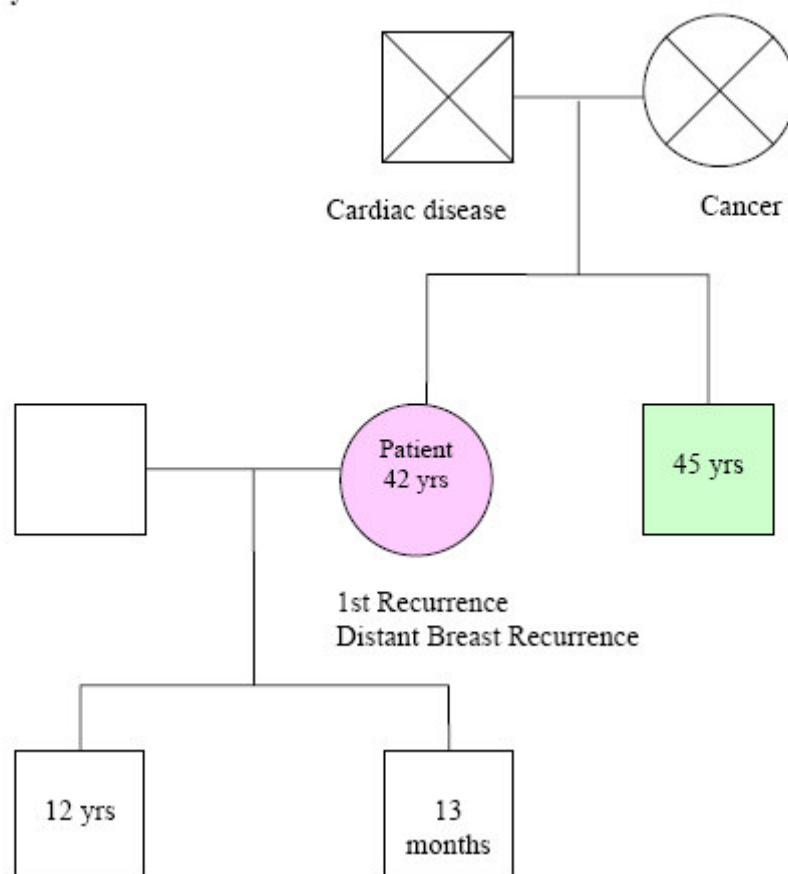
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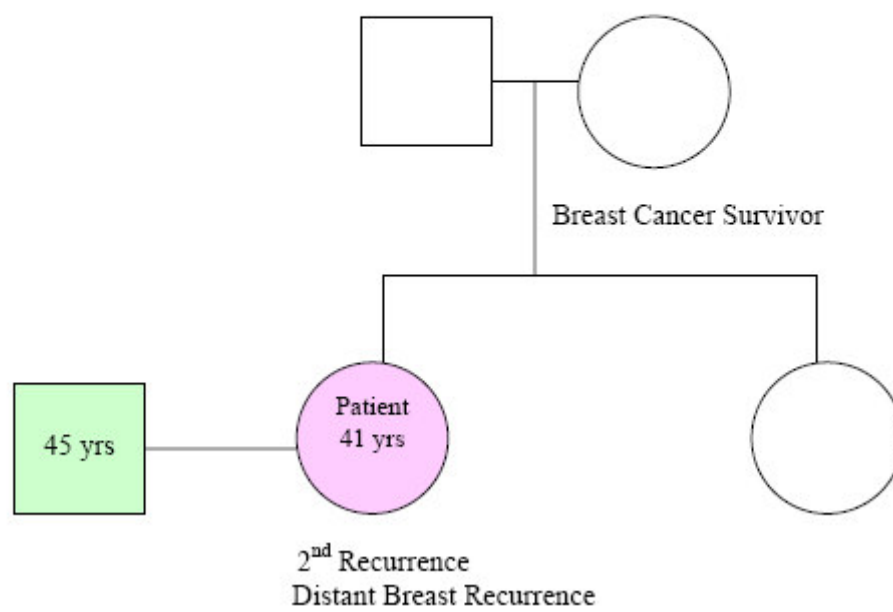
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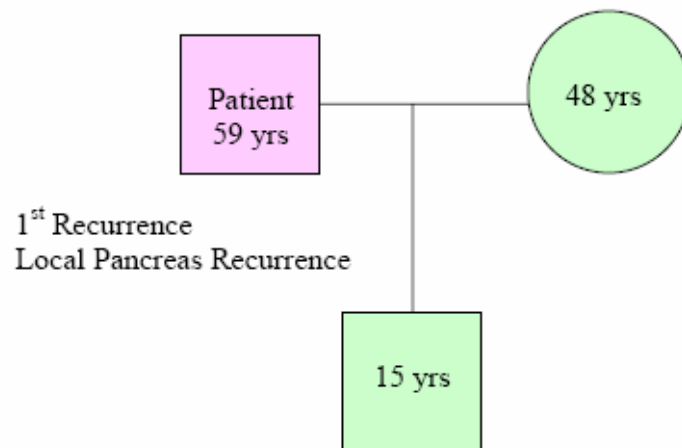
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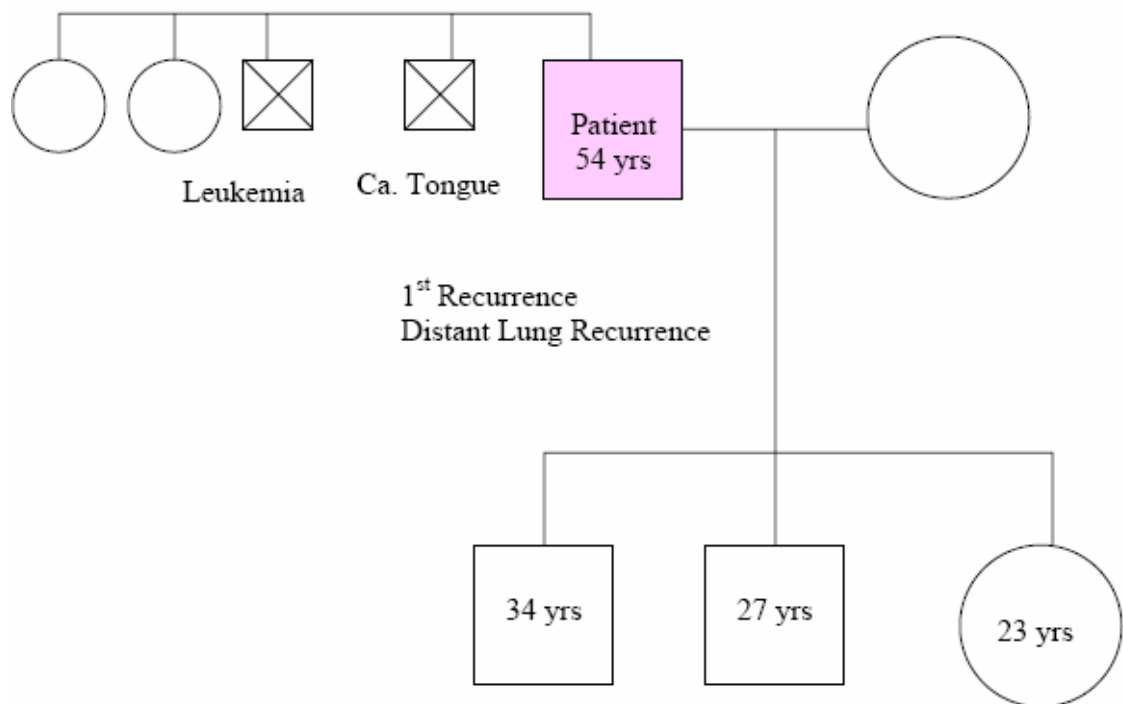
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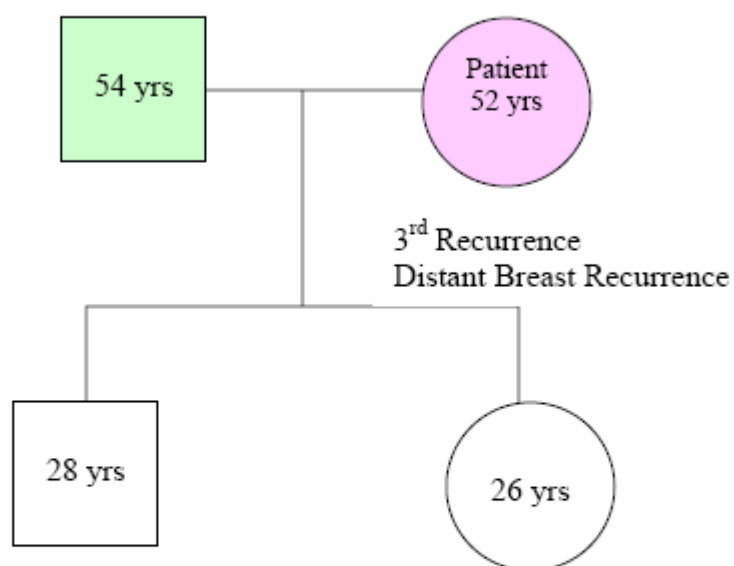
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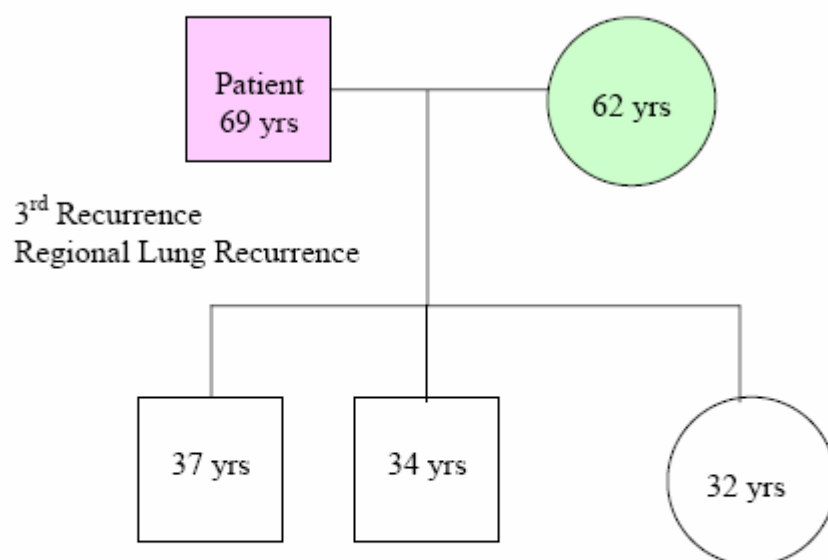
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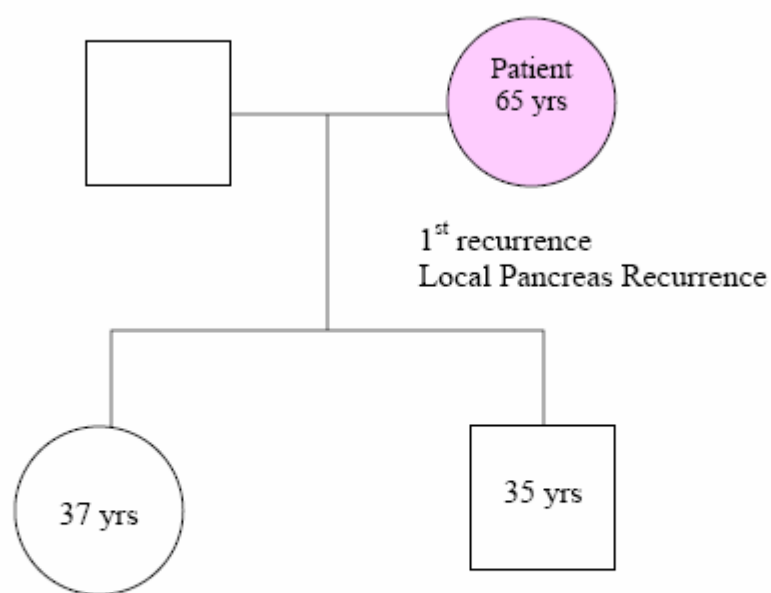
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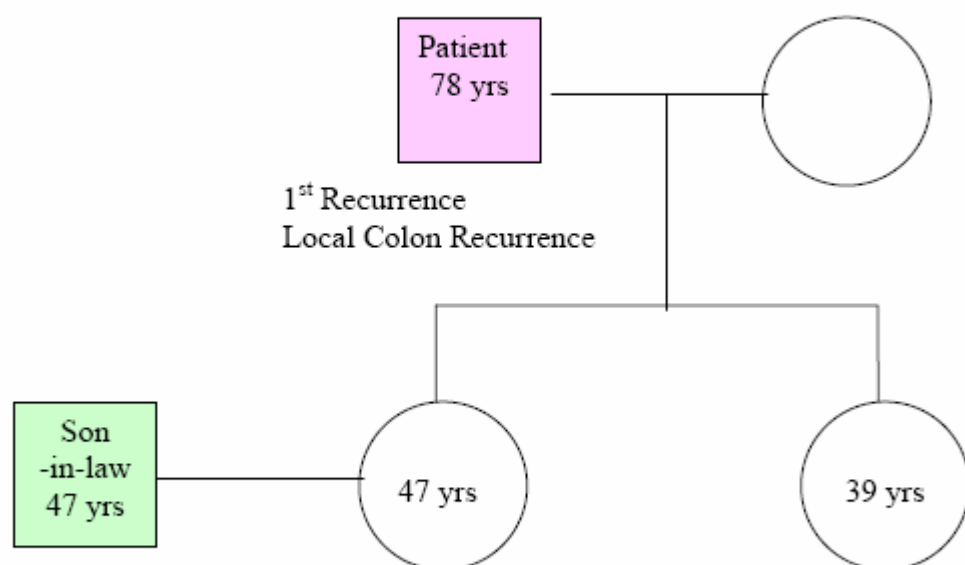
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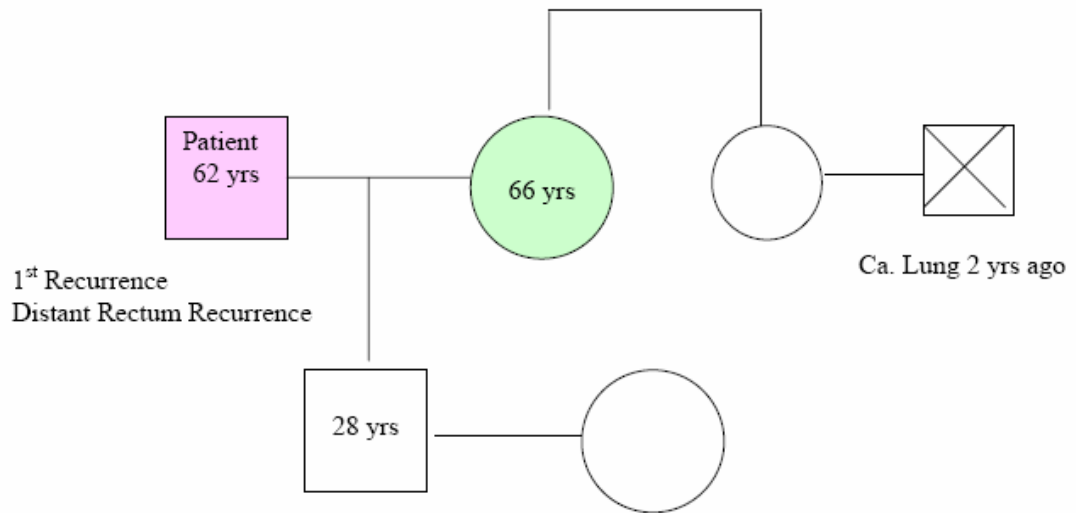
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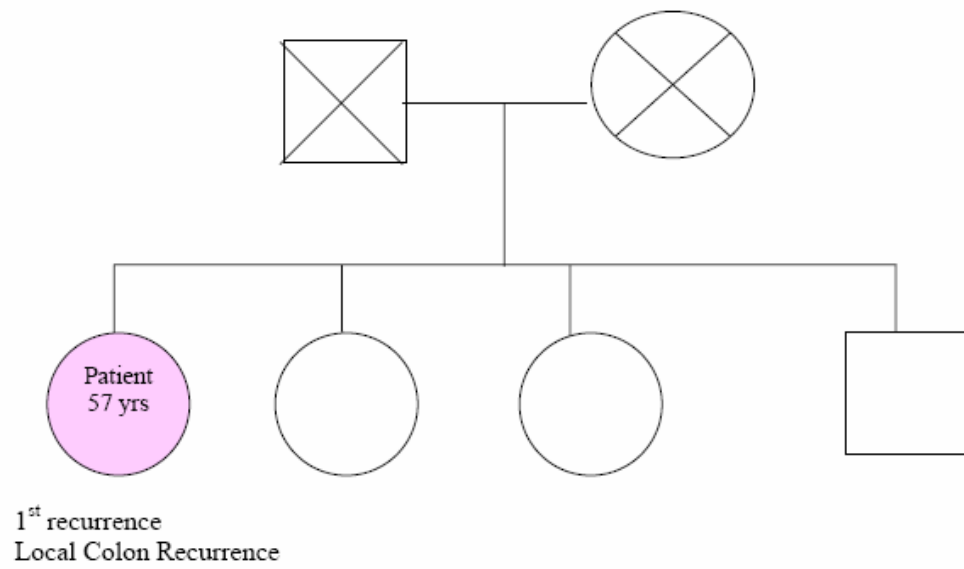
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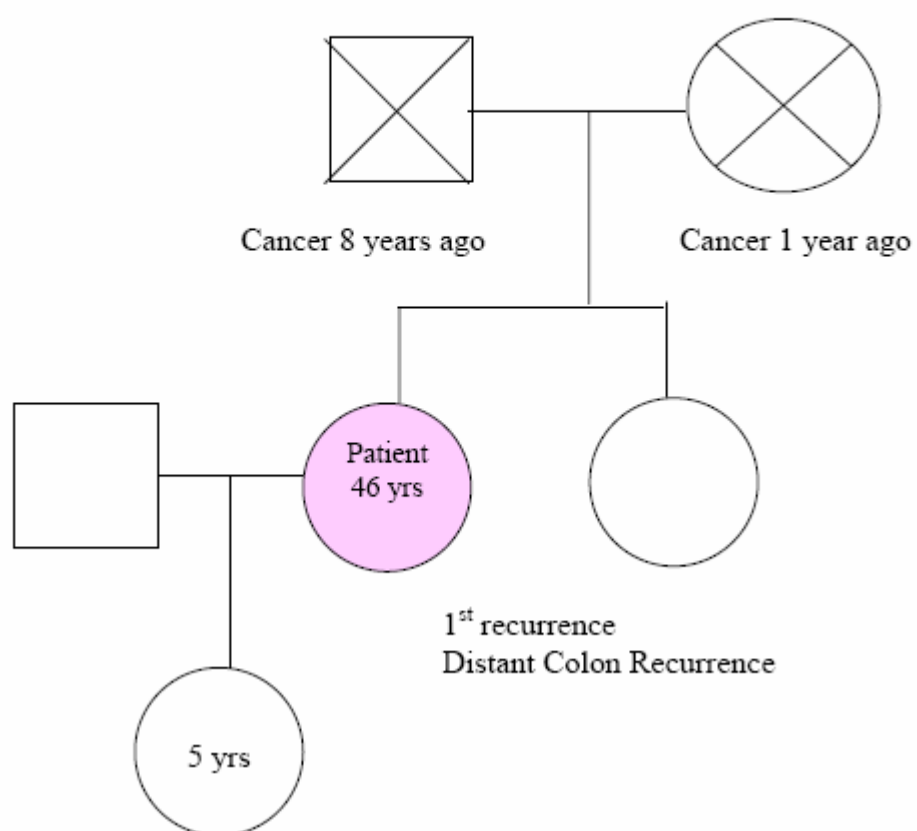
Family 13



Family 14



Family 15



4. Process for approvals from the two centres

APPROVALS FROM THE UNIVERSITY CLINIC

Formal ethics committee approval from the University Clinic was obtained in August 2003. Other formal concerns were also required to start data collection. First, I requested permission to the Director of the centre, who replied to my request positively and encouraged me to conduct the study. In addition, I received verbal consent from the Nursing Director of the centre to carry out the research.

Second, I contacted the nurse-managers of the three wards to present written and verbal information about the study to them separately. After receiving separate approvals from the three nurse-managers, I gave information to all the nurses who worked on the selected wards. I believed that using this approach was important to build a good relationship with nurses, facilitating identification of future participants and helping me to conduct the research in a proper way. A total of three separate meetings were programmed with nurses from the three units. To allow the majority of nurses to participate and avoid any constraints to the nurses' attendance at the meetings, these were conducted at the morning-afternoon shift change time and in a room located in each of the selected settings. The presentation of the study was further supplemented by a document that included a short description of the purpose of the study and its development as well as my contact details. Considerable attention was paid during the meetings and interesting questions were asked, such as where interviews would be conducted or how to contact me when a potential patient-interviewee was found.

In addition to the previous steps, consent was required from the Oncology Medical Department. I formally contacted the director of the Oncology Department and presented the characteristics of the research to him. He considered it advisable to report on the study to all the members of the Department. A complementary meeting was therefore programmed and 14 oncologists and 4 nurses participated. During a one-hour meeting, I presented a formal power point presentation on the research. Time was offered for discussion and questions at the end of the session.

The audience asked about different aspects of the research methodology. The first discussion was about how I would obtain generalisation of the results using qualitative data. I sought to show that grounded theory was a qualitative methodology, which was different from quantitative methodology. In addition, emphasis was paid to the fact that the current research aimed to identify dimensions of cancer recurrence by combining various perspectives into an overall framework of cancer recurrence experiences. A second area of discussion focused on the appropriateness of the inclusion criteria related to the type of treatment patients were undergoing. In the initial research proposal, one of the inclusion criteria was that patients had to be “receiving some form of curative cancer treatment”. However, the doctors highlighted that the use of the term “curative” could be controversial and could hamper recruitment because it was often difficult to guarantee complete cure in cancer. They suggested replacing the term with the sentence “to have a life expectancy of more than 6 months at the time of cancer recurrence”, which was thought to allow a wider range of patient situations and subsequently a wider representation of the sample. The criteria were modified after discussion with my supervisors. Finally, all formal steps were passed and from the University Clinic gave consent to start data collection..

APPROVALS FROM THE PUBLIC HOSPITAL

I first contacted the Director of the Oncology Department of the Public Hospital and had a formal meeting with her. I supplemented the meeting with a short research proposal. In addition, a formal letter addressed to the Director of the Public Hospital was sent in April 2004 asking permission to conduct the study in the Oncology Day Unit. The letter was accompanied by a short description of the purpose of the study and the method of collecting data. In reply to my letter, in June 2004 I received a letter asking me for additional information about the study. A second letter with the required information was personally delivered to the Management Secretariat. Finally, in June 2004, I received written consent to initiate data collection in the Oncology Day Unit of the Public Hospital.

5. Socio-demographic details

DEMOGRAPHIC CHARACTERISTICS: PATIENTS

Sex: ☐ Female ☐ Male

Age: -----

Education: -----

Employment:

☐ Full time ☐ Part time ☐ Housewife

☐ Retired ☐ Unemployed ☐ Sick leave

First tumour: -----

Type of recurrence 1: ----- Type of recurrence 2:-----

Type of recurrence 3:-----

Time since first cancer: -----

Time since diagnosis of recurrence: ☐ Less 1 month ☐ 1 month ☐ 2 months
☐ 3 months ☐ 4 months ☐ 5 months
☐ More -----

N° de recurrence: ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ More than 4 -----

Treatment: ☐ Surgery ☐ Chemotherapy ☐ Radiotherapy
☐ Combination -----

SOCIO-DEMOGRAPHIC CHARACTERISTICS: FAMILY MEMBERS

Family member 1

Sex: ☐ Female ☐ Male

Age: -----

Education: -----

Relationship:

- ☐ Spouse ☐ Partner
☐ Sibling ☐ Mother/Father
☐ Friend
☐ Other

Family member 1

Sex: ☐ Female ☐ Male

Age: -----

Education: -----

Relationship:

- ☐ Spouse ☐ Partner
☐ Sibling ☐ Mother/Father
☐ Friend
☐ Other

SOCIO-DEMOGRAPHIC CHARACTERISTICS: NURSE

Sex: ☐ Female ☐ Male

Age: -----

Cancer training: ☐ Yes

☐ No

Years as qualified nurse: -----

Years in cancer nursing: -----

6. My published papers in the field of cancer nursing

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Posted At: 21 November 2006 15:05

Posted To: Journals Rights

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Subject: Request permission to reprint my articles to be included in my thesis

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- Vivar C.G. & McQueen A. (2005) Informational and emotional needs of long-term survivors of breast cancer. *Journal of Advanced Nursing* 51, 520-528.

- Vivar C.G. (2006) Putting conflict management into practice: a nursing case study. *Journal of Nursing Management* 13, 1-6.

Thank you very much.
Yours sincerely,
Cristina G. Vivar

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Laura Wilson.

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Posted At: 24 November 2006 10:07

Posted To: November 2006

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Subject: Request permission to reprint my articles to be included in my thesis

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- Vivar C.G. (2006) Long-term cancer survivors. "Who is there to work with these people?" *European Journal of Cancer Care*, Published article online: 24-Aug-2006, doi: 10.1111/j.1365-2354.2006.00689.x

Thank you very much.

Yours sincerely

Cristina G. Vivar

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Este mensaje ha sido enviado desde <https://webmail.unav.es>

Informational and emotional needs of long-term survivors of breast cancer

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VIVAR C.G. & MCQUEEN A. (2005) *Journal of Advanced Nursing* 51(5), 520–528
Informational and emotional needs of long-term survivors of breast cancer

Aims. This paper presents a review of the informational and emotional needs of long-term breast cancer survivors, with particular attention to the different needs of women according to their age and to critiquing healthcare provision to these women.

Background. Women with a history of breast cancer are the largest group of cancer survivors. While they may be disease-free, their cancer diagnosis has ongoing physical and psychosocial implications for their lives and well-being.

Methods. A literature search for the period 1985 to March 2004 was undertaken using the CINAHL, MEDLINE, CANCERLIT, PubMed and CUIDEN databases and the keywords long-term, breast cancer survivors, needs and social support. Hand-searching was also done, and reference lists of papers were examined for relevant studies.

Results. Survivors of breast cancer continue to experience informational and emotional needs during their long-term survivorship, and variation in the amount and type of support required is age-related. However, women's needs are often unmet by oncology teams and they have to find other sources of support, such as self-help groups. Thus, ongoing care is required after completion of medical treatment, and nurses have a significant contribution to make here.

Conclusions. Nursing research on long-term breast cancer survivorship is limited. Future studies need to investigate the unmet needs of long-term survivors of breast cancer and, specifically, explore the kind of support women would like to receive from oncology teams, and particularly from breast cancer nurses.

Keywords: breast cancer survivors, information, needs, nursing, support

Introduction

Mullan (1985), a physician diagnosed with cancer, conceptualized the cancer experience as 'seasons of survival' that comprised three main stages. First, the experience surrounding the initial diagnosis of cancer was defined as 'acute survival'. Second, 'extended survival' was the term used when a person with cancer was dealing with the uncertainty of

treatments and prognosis. Finally, 'permanent survival' existed when the person was considered to have been cured of cancer but still experienced its physical and emotional impact. This last season has been defined as a cure, a disease-free state, or more commonly as long-term survival.

Before proceeding it is appropriate to define what is meant by a long-term breast cancer survivor. While definitions of the term differ in the literature, in this paper a long-term

breast cancer survivor will be defined as a woman diagnosed with breast cancer who has lived beyond 5 years without recurrence. Although she is disease-free, she may experience physical and psychosocial consequences of breast cancer. Five years after diagnosis is taken as the starting point for long-term survivorship because most recurrences occur within 5 years of diagnosis (Gotay & Muraoka 1998). In this study men were excluded because, although they can get breast cancer, this is very rare.

Advances in technology, more aggressive treatments, and earlier and improved detection of breast cancer have led to an increase in survival. An improved 5-year survival rate for women diagnosed at an early stage of the disease has been reported (Gotay & Muraoka 1998). Indeed, women with a history of breast cancer are the largest group of cancer survivors, followed by those with prostate cancer (Yancik & Ries 1994, Rowland *et al.* 2001).

Of the three seasons described above, the acute and extended survival stages have been extensively reported over the past two decades (Ferrell 1996, Ganz *et al.* 1996, Ferrell *et al.* 1997, 1998, Dow & Lafferty 2000). In addition to considering the large number of long-term breast cancer survivors, researchers have begun to pay attention to the quality of life of this population (Wyatt & Friedman 1996, Ferrell & Dow 1997, Pedro 2001). Indeed, studies reveal that long-term survivors of breast cancer, although free of disease, may experience biomedical and psychosocial concerns such as problems related to body image (Omne-Ponten *et al.* 1994, Dorval *et al.* 1998), continued menopausal symptoms (Snyder *et al.* 1998, Carpenter & Andrykowski 1999, Ganz 2001), problems of fertility and pregnancy (Shapiro & Recht 1994, Surbone & Petrek 1997, Thaler-DeMers 2001), employment concerns (Rendle 1997, Stewart *et al.* 2001, Spelten *et al.* 2002), difficulties with health insurance cover (Stewart *et al.* 2001) and fear of cancer recurrence (Cella *et al.* 1990, Dow *et al.* 1996, Mahon & Casperson 1997).

It is crucial that nurses and other healthcare professionals are aware of the potential physical and psychosocial effects that breast cancer survivors might experience during long-term survivorship if these women are to receive the ongoing professional support that can enhance their quality of life.

The study

Aims

This paper is not intended to be a review of the psychosocial sequelae of long-term survivors of breast cancer, as this will

be addressed in a future paper. Rather, the aims of this paper are:

- To present a literature review of the scanty work on the informational and emotional needs of adult long-term breast cancer survivors, and particularly on the different needs of younger and older women.
- To critique the approach taken by healthcare services with breast cancer survivors.
- To examine the role of self-help groups with this population.

Search methods

An electronic search was conducted using the CINAHL, MEDLINE, CANCERLIT and PubMed databases and CUIDEN, which is the Spanish nursing database, this being the first language of one of the authors. The inclusion criteria for the review were that documents were: (1) primary descriptive or quantitative research, literature reviews and the other documents and (2) those published between 1985 and March 2004. Keywords used were long-term, breast cancer survivors, needs and social support, and all terms were used in different combinations. To ensure that studies focused on specifically on long-term survivors of breast cancer, it was initially decided to retrieve documents that contained the words 'long-term' within their title or abstract. However, a lack of consensus was found in defining long-term survivorship. Therefore, the literature examination was amplified to include publications that did not specify survival time within their title or abstract. Studies judged to provide information relating to cancer survivorship were examined. In the case of primary research, if information about the purpose, methodology, sample characteristics and results was given, the study was considered for the review. In the case of literature reviews and reports, these were only considered if they addressed the question of cancer survivorship. In addition, hand-searching and reference lists of papers were reviewed and further papers were identified. Interestingly, no publication in Spanish was found on this topic.

Most of the research related to individual needs in breast cancer sampled newly diagnosed women only (Derdarian 1986, Luker *et al.* 1996), short-term breast cancer survivors (Bilodeau & Degner 1996, Shimozuma *et al.* 1999, Lindop & Cannon 2001), or used the point of diagnosis as a reference point to examine long-term survivors' needs retrospectively. However, only research that focused on the long-term survival phase of the cancer trajectory was considered for this review, with the exemption of the study by Thewes *et al.* (2004). This was mainly because,

although participants in the study were short-term breast cancer survivors, Thewes *et al.* (2004) present preliminary qualitative data on their age-specific needs. Papers addressing paediatric cancer nursing were excluded from the review.

Using this variety of search strategies helped to identify additional research that was not included in the databases but was relevant to the review. Nevertheless, while the literature review sought to represent the international cancer nursing literature, it is fair to say that it probably included only a proportion of it because solely studies in English were included.

The concept of need

Before considering the individual needs of long-term survivors of breast cancer, it is important to clarify the concept of need. There is a variety of definitions and dimensions of the concept according to the discipline drawn on to define the term. However, it is not the aim of this paper to present distinct perspectives on the concept of need, which first was interpreted by the philosophers Marx and Hegel, as noted by Fraser (1998). Rather, the purpose of this section is to elucidate the concept of need from a health perspective. According to Liss (1993), a Swedish philosopher who examined the concept of need for health care, needs exist when there is a gap between a person's actual state and their goals. Along similar lines, Heather (1955) defined need as a perceived deficit that is a requisite which, when fulfilled, achieves satisfaction of a goal.

Need is a central concept in oncology but it is also, as Smith (1980) stated, 'a confused and sometimes confusing concept' (p. 1). There is commonly confusion in the literature between the terms need and sequel of an illness. However, it is important to differentiate between the two. While a need is the circumstance in which something is necessary, or which requires some course of action, a sequel is a condition which is the consequence of a previous disease or injury (The New Oxford Dictionary of English 1999). Seedhouse (1994) also distinguishes needs from problems, in that needs are means to ends; needs are *for* something, whereas problems or concerns can simply exist.

Thus, needs exist when there is a difference between a person's actual state and the optimal level of health. With regard to long-term breast cancer survivors, a need exists when there is a difference between women's actual state (physical and psychosocial consequences of breast cancer) and the optimal state (reduction or absence of sequelae). Therefore, knowledge about long-term survivors' needs is

necessary in order to help women attain good quality of life.

Individual needs of long-term survivors of breast cancer

While a number of studies have focused on appraisal and psychological responses of survivorship (Halstead & Fernsler 1994, Deimling *et al.* 2002, Bowman *et al.* 2003), only a few have examined the needs of long-term survivors of breast cancer. Gray *et al.* (1998) conducted nine focus groups across Ontario to identify the information needs and preferences of well breast cancer survivors 4 years or more after diagnosis. Two broad categories emerged: (a) the context within which women sought information, and (b) the content of information that was desired and sought. Some themes concerning the context were: the ongoing impact on women of their initial disease experience and continued fear of recurrence; lack of information and understanding about treatments; and concerns related to communication with healthcare professionals. Important themes related to content issues included: lack of information about follow-up protocols, tamoxifen, detecting symptoms of recurrence, prevention for daughters, and lifestyle.

While one must be cautious in generalizing from such a study, the findings show that long-term survivors of breast cancer can continue to have informational needs and that these are not being met by physicians and oncology teams. The diminishing communication between physicians and women completing their cancer treatment was also highlighted by Luker *et al.* (1996). This lack of medical support led women to find complementary sources of information, such as books, popular media, the Internet and self-help groups.

Wilson *et al.* (2000) studied how to improve the lives of rural breast cancer survivors in Washington communities and suggested focus group discussions in an attempt to meet their needs. The sample included 128 women between 25 and 77 years old, and with survival times ranging from 1 to 32 years. Their findings reflected those of Gray *et al.* (1998) that the needs of many women were not being met. Moreover, one of the most important findings that emerged from the study by Wilson *et al.* (2000) was a support difference between women diagnosed with late-stage cancer and women diagnosed with early stage cancer, so that women diagnosed with late-stage cancer were being treated inadequately by the cancer team. A need for extended support and educational services were suggested by all women, and particularly by those with late-stage disease because they experienced more continuing difficulties and less satisfaction with medical care.

There is no doubt that the preceding studies have expanded our knowledge of the needs of breast cancer survivors, and have shown that most long-term survivors of breast cancer need extended emotional and informational support. While there may be differences related to age, none of these studies have distinguished between the needs of younger and older long-term survivors. Furthermore, the study by Wilson *et al.* (2000) included women with a survival time ranging from 1 to 32 years, but differences in needs were not reported between short- and long-term survivors.

It seems that papers on the concerns of long-term survivors of breast cancer fail to address different needs. However, it is anticipated that not all needs are equally present, and may differ depending on years of survival, age at diagnosis, perceived social support and culture.

Age differences in needs

Recently researchers have begun to examine the impact of age-related changes in women with breast cancer. A growing body of evidence suggests that young women with breast cancer have different concerns than older women (Vinokur *et al.* 1990, Bloom & Kessler 1994, Northouse 1994, Schrover 1994, Dunn & Steginga 2000, Sammarco 2001). Literature on short-term survivorship of breast cancer has demonstrated that age at diagnosis has an impact on the recovery process. However, most of the research on long-term survivors does not present years of survival as a variable. Only a few papers have alluded to the impact of age-related changes in long-term breast cancer survivors.

In evaluating the self-assessed support needs of breast cancer women living in United Kingdom (UK), Lindop and Cannon (2001) found differences between women in different age ranges and at different points on the cancer trajectory. In their study, the younger age group (20–45 years old), and to a greater extent, the middle-aged group (46–53 years old) expressed statistically significantly more and different needs than the older group (54 years old and over). For instance, body image and femininity were important to the middle-aged group. Also, women facing the acute phase of treatments reported higher needs related to how to deal with symptoms than those adjusting to short-term survival.

While the preceding study contributed to knowledge about the needs of women according to their age, it did not take into account the length of survival. As a result, possible differences between short- and long-term survivors were not reported. Also, because the sample was not representative of long-term survivors, its generalizability is limited.

Of the reviewed papers on age at diagnosis and quality of life in breast cancer, only an American cross-sectional study

compared the impact of breast cancer on long-term survival across age groups (Cimprich *et al.* 2002). Its purpose was to examine how younger (27–44 years), middle (45–65 years) and older (> 65 years) life stage at diagnosis of breast cancer could influence current quality of life in long-term survivors. To assess quality of life (QoL) outcomes, participants completed the Quality of Life-Cancer Survivors (QoL-CS) instrument, a tool that evaluates four domains of QoL (physical, psychological, social and spiritual). Women who had been diagnosed at an older age reported poorer physical well-being than did those diagnosed at a younger age or in middle age. In the social domain, younger women reported greater impact on sexuality and family distress than did those in the other two groups. In the psychological domain, women in all age groups reported moderate fears of recurrence and development of a second cancer. In the spiritual domain, older women reported fewer positive changes as a result of the diagnosis than did younger women. In relation to overall QoL, middle aged women reported better overall QoL than younger or older ones did. Of major interest was that more than 5 years of survivorship led to improved overall quality of life.

While Lindop and Cannon's (2001) study did not address the survival period of women in different age groupings, it is interesting to compare their findings with those of Cimprich *et al.* (2002). While the focus of these studies was different, as well as the means of data collection, both revealed that age was important in relation to needs. It is also noteworthy that, although the two studies were conducted with participants from different cultures (British and American), common needs were identified related to age.

The study by Cimprich *et al.* (2002) was unique in that it was designed to explore specific differences between young and older long-term breast cancer survivors in overall quality of life. However, the quantitative approach failed to examine the meaning of the areas of concerns linked to age differentials.

The only paper identified for this review that explored qualitatively the shared and unique needs of younger and older short-term survivors of breast cancer was a recent Australian study by Thewes *et al.* (2004). To gather qualitative data on the unmet psychosocial needs of both young and old breast cancer survivors, 18 formal semi-structured telephone interviews were conducted by a female clinical psychologist. Three main areas of interest were identified: (1) impact of cancer, (2) psychological and support needs and (3) information needs. Whereas some psychosocial needs were shared by both older and younger survivors, other needs seemed to be unique to certain age groups. The majority of the women reported a need to be reassured that late effects

caused by past antitumoural treatments, such as aches, pains or fatigue, were not a sign of recurrence. Both younger and older women also expressed a need to be informed about how to deal with physical problems, such as arm problems. Overall, younger survivors reported more unique unmet needs regarding menopause and fertility issues than older women. Moreover, some younger women expressed a need for further information and counselling about changes in their work activities and careers. In contrast, some older breast cancer survivors expressed a need to not receive information. Regarding psychological functioning, younger survivors reported more need for emotional support from professionals than older women. Finally, important evidence about support services emerged, in that younger survivors experienced a sense of isolation when accessing both professional counselling and support groups. This was mainly due to a younger survivor with a diagnosis of breast cancer, as most survivors were postmenopausal women.

The study by Thewes *et al.* (2004) provided useful preliminary information about age-difference psychosocial needs among younger and older survivors. Moreover, it disclosed original data about the unmet needs of many younger survivors attending support services. However, the findings cannot be generalized to long-term breast cancer survivors, as the participants were all short-term survivors (from 6 to 24 months since completion of cancer treatment).

Overall, the studies reviewed show that age is a meaningful variable that should be kept in mind when caring for breast cancer survivors and when conducting research with these women. In addition, the information and emotional needs of short-term breast cancer survivors appear to differ according to age (Lindop & Cannon 2001, Thewes *et al.* 2004). However, more work is necessary on assessment of age-related needs of well long-term survivors of breast cancer.

Support for long-term breast cancer survivors

In the UK cancer services have undergone important changes in the last 10 years (Rumsey & Harcourt 1998, Hutchison 2001). The Calman-Hine Report, 'A Policy Framework for Commissioning Cancer Services' (Calman & Hine 1995), provided a vision for a uniformly high standard of care that was fast, convenient and patient-focused. Cancer survivorship research has been identified as a priority for cancer services (Aziz 2002, Richardson *et al.* 2002). However, there appears to be little consensus as to how follow-up after treatment for breast cancer can be achieved (Fawzy *et al.* 1995, Hurria & Hudis 2003, Partridge *et al.* 2003), perhaps because 'the current system of follow-up is traditionally

routinized and lacks an individual approach' (Pennery & Maller 2000, p. 139).

Although numerous studies have shown that long-term survivors of breast cancer experience physical and psychosocial consequences which may even worsen over time, healthcare professionals do not provide adequate support to these women. According to Holzner *et al.* (2001), this may be because health carers consider survivors to be cured, and thus pay less attention to their emotional situation. They may not always have the amount of time they would wish to spend on assessing the needs of service users.

It is, however, worth asking how long-term survivors feel about health service care. Adewuyi-Dalton *et al.* (1998), investigating the experience of specialist hospital follow-up among 109 women with breast cancer in remission, revealed that discontinuity of care led to communication difficulties. Although not visible in all studies, women may regret losing the special, individualized attention they had when they were undergoing treatment. Consequently, feelings of abandonment occurred (Gray *et al.* 1998).

Long-term survivors, then, may feel that they are not well-supported by healthcare professionals, and particularly by physicians (Gray *et al.* 1998). Certainty, the transition from patient to survivor is a difficult one (Seligman 1996), and women may feel they are not well supported during follow-up care (Pelusi 1997). As a result, those who have informational and emotional needs which are not satisfactorily met by formal healthcare systems have to find other sources of support. Family, friends and self-help groups provide alternative and complementary services to those provided by the state (Fredette 1995, Gray *et al.* 1997, Pistrang & Barker 1998). Self-help groups need to be distinguished from professionally led support groups, although this has not always been done in the cancer literature (Hitch *et al.* 1994). While support groups are formed by clients who receive help and healthcare professionals who provide help, in self-help groups members can be both help givers and recipients (King & Moreggi 1998).

Cancer self-help groups

Most long-term survivors cope effectively with the psychosocial issues they face. However, advice and help from informal social support and particularly from self-help groups appear beneficial (Waxler-Morrison *et al.* 1991, Platz 1993, Ferrans 1994, Cope 1995, Hoskins *et al.* 1996). The number of breast cancer self-help groups is increasing (Gray *et al.* 1997), and they attempt to provide what women find is not available within the formal services (Seligman 1996).

What is already known about this topic

- Long-term breast cancer survivorship is an emerging concept in cancer nursing care.
- There are numerous studies of the physical and psychosocial sequelae of long-term cancer survivors of breast cancer, but few addressing their needs.

What this paper adds

- Clarification of the concepts of need, problem and sequelae in the context of long-term survival after breast cancer.
- While long-term survivors may be disease-free, they can have ongoing informational and emotional needs.
- The scarcity of nursing evidence on this topic limits the effectiveness of nursing care for cancer survivors.

Social support plays a vital role in giving emotional help (Bloom *et al.* 1991, McLean 1995, Lewis *et al.* 2001), preventing perceptions of uncertainty (Wonghongkul *et al.* 2000), and promoting overall quality of life in long-term breast cancer survivors (Lee 1997). In addition, informal social support can help by mitigating the negative psychosocial effects (Wyatt *et al.* 1993, Sammarco 2001), and by seeking to meet the needs of long-term survivors of breast cancer.

As time passes and breast cancer survivors carry on with their lives, their need for a large supportive network decreases (Neuling & Winefield 1988, Sammarco 2001). However, sharing ideas with others in a similar position can help women understand the course of survivorship and see that the sequelae of breast cancer are not unique to them.

A Canadian study by Gray *et al.* (1997) explored the experience of women in four community breast cancer self-help groups in Ontario. Semi-structured interviews were conducted with 24 women between 33 and 73 years old and with survival times ranging from one to more than 5 years. Three broad categories emerged from the interviews: emotional support benefits; informational and practical benefits; and group processes and structures. Self-help groups were beneficial in meeting the emotional needs of short- and long-term survivors. Sharing experiences and information with other women and feeling understood seemed relevant to participants. Other studies have confirmed that participation in groups alleviates a sense of loneliness, provides a sense of belonging, and offers emotional and social support (Adamsen & Rasmussen 2001). In addition, individuals involved in advocating for others have found this to be an empowering experience (Zebrack 2001): in the process of helping others, breast cancer survivors help themselves.

Although cancer self-help groups have been shown to meet the information needs, and particularly, the emotional needs of short- and long-term breast cancer survivors, feelings of isolation can still be experienced by young women when they attend support groups (Thewes *et al.* 2004). Self-help groups are therefore encouraged to recognize distinct age-specific needs and take measures to reduce feelings of isolation experienced by younger women.

Conclusion

Nursing as a profession has a central role in all phases of the cancer trajectory, including survivorship (Ferrell *et al.* 2003). Oncology nurses have unique opportunities to help survivors because they work in a variety of contexts, such as hospitals, community health settings and homes. Furthermore, oncology nurses are often the healthcare professionals to whom survivors return after treatments have ended (Hinds *et al.* 1995).

Despite the work of nurses in cancer survivorship, there is little in the nursing literature for those who wish to understand better the needs of long-term survivors in relation to nursing practice. It is rather the medical and psychological literature that offers a wealth of information about this topic. Thus, it is perhaps not surprising that much of the research conducted with cancer survivors give scant details of the type of care oncology nurses provide to these women, and its effectiveness is hidden. It is therefore important that future research focuses on nursing management and investigates the unmet needs of long-term female survivors of breast cancer, explores optimal kinds of support, and examines the particular contribution of breast cancer nurses. This information could help oncology nurses to plan initial and follow-up care for women with breast cancer. It is also important to implement educational and supportive programmes to help and empower women through their survivorship.

Finally, much of the evidence on survivorship is in the American and Canadian literature (Gray *et al.* 1998, Wilson *et al.* 2000, Cimprich *et al.* 2002, Thewes *et al.* 2004). However, needs are partly determined by culture (Holmes & Warelw 1997). Therefore, the needs of long-term breast cancer survivors from different cultural contexts and different healthcare systems should be investigated. A phenomenological study would be appropriate to explore survivors' needs, experiences and perspectives. Collaborative research incorporating participants from different cultures could highlight any cultural differences, as well as any general age-related differences. This knowledge would be valuable for nurses and others caring for women from a variety of cultural backgrounds.

Author contributions

CGV was responsible for the study conception and design, undertook data collection and analysis and drafted the manuscript. AM performed critical revision of the manuscript for important intellectual content and undertook supervision.

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Putting conflict management into practice: a nursing case study

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Putting conflict management into practice: a nursing case study

Aim This paper is intended to put knowledge in conflict management into practice through reflecting on a nursing case study.

Background Nursing organizations are particularly vulnerable to conflict as the context of nurses' work may be difficult and stressful. Power conflict is argued to be an important source of tension within nursing units. Learning to manage conflict at an early stage is therefore crucial to the effective functioning of nursing organizations.

Evaluation A nursing case study that illustrates power conflict in an oncology nursing unit is displayed and reflection on conflict management from the case is provided.

Key issues There is no appropriate or inappropriate strategy to deal with conflict. However, detecting initial symptoms of conflict and adopting the most effective behaviour to conflict resolution is essential in nursing units.

Conclusion Further nursing education in conflict management for staff nurses and nurse managers is greatly needed.

Keywords: conflict, conflict management, nursing case study

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Introduction

Conflict has in the past been regarded as damaging and harmful (Cowling *et al.* 1988). However, behavioural scientists have studied and concluded that not all conflict is destructive and that a certain degree of conflict is essential (Cowling *et al.* 1988). Health care organizations are particularly vulnerable to conflict as the context and nature of health care professionals' work may be difficult and stressful (Hipwell *et al.* 1989). Managing conflict is therefore crucial to contribute to the effective functioning of nursing organizations and consequently, to the excellence of nursing care.

Although some research (Healy & McKay 1999, McGowan 2001, Cox 2003) has focused on the sources

and effects of conflict in nursing units, there are various sources of conflict in today's health care environment. Some of the most important sources of conflict in nursing settings are divergent management style and staff perspectives, limited staff resources in the unit resulting in higher levels of stress, differences in goals among work groups and competition (Kunaviktikul *et al.* 2000, McVicar 2003). In addition, an important source of conflict in the nursing unit is the nurse–doctor dyad. Numerous studies have focused on the relationship between these health care professionals (Fowkes & Mentink 1994, Forte 1997, Keenan *et al.* 1998). Traditionally, nurses have operated in compliance with doctors' instructions. However, nurses have begun to reject the traditional paradigm of doctor dominance and

nurse deference. As a result, nurses have acquired greater responsibility for decision making (Katzman 1989), which has led to increased conflict between nurses and doctors (Prescott & Bowen 1985, Jervis 2002). Moreover, changes in organizational structures have also been one of the main sources of increased conflict, as discussed by Johnson (1994). Changes in health care organizations, such as the incorporation of new policies in the National Health Care Service, have resulted in higher levels of disagreements and conflicts (Broome 1990).

Power conflict is without doubt another significant factor for conflict. It refers to the conflict between different status levels 'A has power over B to the extent that he can get B to do something B would not otherwise do' (Dahl 1957 cited in Cowling *et al.* 1988, p. 197). In other words, the relationship boss-subordinate may at times lead to conflict. A number of management studies have analysed the relationship between superiors' role and a subordinates' role with regards to subordinates' choices of style in superior-subordinate conflicts (Rahim 1985, Johnson *et al.* 1990, Cavanagh 1991). Differences in styles of conflict management between subordinates and superiors have been found (Blake & Mouton 1968). While superiors often used competition, compromise and collaboration to handle conflict, subordinates opted for collaboration, avoidance and dominance (Rahim 1985). An illustrative example of this hierarchical relationship can be the dyad head nurse-nursing staff. There are occasions where the leader's authority (head nurse) is challenged by his/her own subordinates (staff nurses). This may be due to disagreement between the leader's demands and the subordinates' own orientation (Heap 1985, Cowling *et al.* 1988). Likewise, there are times when the head nurse leadership is so flexible that staff nurses can feel lost and abandoned. When these situations are severe and persistent, conflict may emerge leading to inadequate health care delivery. According to Forte (1997), such conflict among health care professionals has an influence on patients. Therefore, to learn to manage and resolve conflict in the most effective way should be a priority among nurses, doctors and other health carers.

This paper is not intended to be a review of conflict management in terms of its assumptions and procedures. Moreover, it is not intended to present the findings of an empirical piece of research on the distinct stressors nurses may experience in their workplace, as this has been addressed elsewhere (French *et al.* 2000). Rather, the aim of this paper is to put knowledge in conflict management into practice. For this purpose, a nursing case study that describes conflict between a head nurse and her nursing staff is displayed and

reflection from the nursing case on conflict management is provided. Finally, a discussion about personal concerns on the topic will be presented.

A nursing case study

The following case study illustrates an oncology setting at a hospital. The nursing team is composed of a head nurse who is in charge of the ward and 11 staff nurses. There are five trained registered nurses who have worked in the service for about 9 years, and six new registered nurses. Although it seems that staff nurses and the head nurse work together in perfect harmony, conflict occurs between them. An excess of authority and power on the part of the leader (head nurse) appears to be the main source of conflict in the service. However, no member of the nursing staff seeks to bring up this uncomfortable situation, as they are concerned about losing their job or making matters worse. Nurses' conflict management is handled through silence and inaction.

What is conflict

Before proceeding, it seems necessary to first clarify the meaning of conflict. Although there is no universal accepted definition of conflict (Albanese 1981), views of the term differ according to how it is defined. Conflict can be seen as functional or dysfunctional, this difference depending on how each person perceives it, manages it and resolves it. According to Thomas (1992), conflict is 'the process that begins when one party perceives that the other party has negatively affected, or is about to negatively affect, something that he or she cares about' (p. 653). In Thomas's (1992) view, conflict is an undesirable phenomenon that leads to negative effects. Nevertheless, as previously mentioned, conflict should not be solely regarded as dysfunctional. Far from it, conflict is also constructive, as it can be catalytic to new ideas, progress and positive change and growth (Rahim 1986, White 1998). Indeed, conflict increases creativity and innovation, provides more energy and motivation, offers people the opportunity for personal growth and healthier relationships, encourages self-examination and fosters reappraising of the situation (Smyth 1985). It is also of importance to note that when the level of conflict is extreme, sabotage and violence can appear within the group. At this stage, conflict may hinder the effectiveness of the group, leading to the reduction group satisfaction, or the group's life can be threatened (Robbins 1978).

Detecting initial symptoms of conflict in a group such as a nursing unit is thus important to solve problems before they reach a stage of difficult resolution (Keenan *et al.* 1998, Skjorshammer 2001). Besides, people have to determine which type of conflict they have to deal with. Fritchie (1995) distinguished between 'hot' and 'cold' conflict. While hot conflict leads to creativity and activity between the parties, cold conflict hinders communication because the conflict is denied. Therefore, for conflict to be managed efficiently, it is important to recognize what the nature of the conflict is and how it will be managed and resolved.

Approaches to conflict resolution

Five common approaches or strategies to conflict resolution have been identified within the literature: competition, avoidance, accommodation, compromise and collaboration (Blake & Mouton 1968, Thomas 1976; Rahim & Magner 1995). First, competition or forcing is a win-lose orientation. It designates a situation in which one person or group attempts to acquire complete dominance. This strategy is appropriate when quick decisions are vital and there is no time for discussion, such as in an emergency. However, it leads to winners and losers. Secondly, avoidance is employed to deny the person, issue or the situation. People or groups using this approach ignore that a problem exists. Therefore, there is no active resolution of the conflict. This conflict behaviour is described in the literature as a 'generally disapproved strategy' (Smyth 1985). However, avoiding a situation until more information is available and an analysis of the problem has been made could be an adequate approach of handling conflict. Robbins (1978) and Rahim (1986) found that the avoidance mechanism was a very effective way to affront a conflictive situation at short-term. However, when avoidance lasts long time it may be dysfunctional, as it prevents recognition that a problem exists. The third strategy, accommodation, also called 'giving in', is the antithesis of competition where cooperation is high and assertiveness low. It refers to the conciliation that occurs when one person or group is willing to yield to the other. Accommodation, at times, can appear relevant, as it encourages people to express themselves. This results in an agreeable relationship between both parties (Skjorshammer 2001). The fourth strategy, compromise, emerges when there is negotiation and swapping between both parties. Each person gets something but gives something else up in the process. Finally, the last strategy is collaboration where there is a win-win orientation. Each person or group meets the

problem with equal concern. This approach encourages identification of areas of agreement and disagreement, and selection of a solution to the problem that incorporates both parties' perspectives. This approach is certainly the one that will require the most time to resolve the conflict, but it is the most meaningful to deal with problem.

Reflecting on the nursing case study

The five conflict behaviours have advantages and disadvantages. All the five can each be right or wrong in different situations and under different circumstances. Indeed, context and culture both influence the way a person or group manages conflict (Tjosvold 1982, Rahim 1985, Thomas 1992, Tidwell 1998). When reflecting on the present nursing case study, it can be noticed that both trained and new registered nurses use avoidance as the main strategy for handling the tension with the head nurse. Although using avoidance to conflict resolution may be appropriate when a problem is emerging (Rahim 1986), it seems that this conflict behaviour has been unsuccessful in the present case study. No attempt from the staff nurses to resolve the conflict has been started. As a result, the problem remains present.

While the nursing staff uses avoidance, the head nurse is adopting a conflict behaviour based on competition. The relationship between the head nurse and her subordinates is based on the exercise of authority and obedience. Although it is admitted that the use of competition is adequate when quick decisions are vital, using this approach appears not to be effective in this particular situation. Presumably, this is due to the fact that staff nurses are working in a permanent atmosphere of dominance. Rather than being supportive of the needs of the nursing staff, the head nurse maintains a leadership style that is based on authority and power.

Why have trained registered nurses used avoidance?

Diverse reasons can be set out. First, trained nurses may experience fear of consequence. They may be concerned about what can happen if they reveal that there are problems within the group. The situation can become worse and tension can increase if they express their feelings. As a result, when faced with conflict, they choose to deny the existence of problems in their ward. Such attitude of avoidance has been also identified within literature as a primary strategy used by nurses for handling conflict (Hightower 1986, Cavanagh 1991, Blankenship & Woodward 1992, Skjorshammer 2001, Valentine 2001).

Besides, when conflict occurs, a large amount of energy is spent on seeking to resolve the problem. Trained nurses may prefer to spend time with patients instead of solving a situation that requires a long time and consumes large amounts of energy. Moreover, the fact that the relationship between the head nurse and the nurses is based on the exercise of authority and obedience may have an influence on the way the nurses manage conflict. It must be remembered that nurses have traditionally worked under the paradigm of doctor dominance and nurse deference. Historical sequelae of the authority-obedience context may persist in wards today.

Why have new registered nurses used avoidance?

According to Wright (1989), a group grows in much the same way that a person does. Both elements experience 'an infantile stage of acute dependence, a stage of adolescent rebellion and a more mature adult stage' (p. 64). In some degree this metaphor can also be applied to the incorporation of new nurses to a ward. New registered nurses experience first a stage of dependency towards the nurse manager, then conflicts emerge because of disagreement and finally the nurse becomes mature and expert. If pause for reflection is given, it can be said that the new registered nurses have a dependency relationship towards the head nurse. They regard her as the person having more knowledge, responsibility, information and authority than the others present. Moreover, as in formal and informal groups, trust takes time to establish in the ward. Inexperienced nurses feel uncomfortable in expressing their feelings and disagreements to the group. Therefore, they opt for silence and seek to discover what kind of interpersonal behaviour is the most appropriate within the ward.

Managing the conflict

As emphasized throughout this paper, there is no single way of managing a conflict. That is, there is no appropriate or inappropriate strategy to deal with conflict. It is therefore the responsibility of the person or group to be conscious of the problem, and to select the most suitable strategies depending on the context in which the problem has emerged. Besides, identifying and confronting conflict at an early stage seems of paramount relevance.

Having suggested that neither avoidance nor competition are the most effective strategies to resolve this particular conflict, it seems worthwhile to find out a way of managing this power conflict. A major challenge for the nursing staff would be to develop alternative strategies that may have been useful in the process of

conflict management. Rather than using avoidance as the main strategy to conflict resolution, adopting a collaborative behaviour would appear more appropriate, as it may have allowed the nursing team to identify areas of agreement. Subsequently, a selection of solutions to the conflict would result.

Regarding the head nurse behaviour, it appears that encouraging her to replace her competitive leadership style with an accommodative behaviour would contribute to conflict settlement. This change may have encouraged a two-way communication process, creating a more harmonious climate within the unit.

Discussion

For conflict to be solved, time is essential. Time to discuss problems and find solutions in collaboration of both parties (Tidwell 1998). However, health care professionals are usually so busy with patients that they have not enough time to think about interpersonal conflict. Nevertheless, conflict resolution should be a priority among nursing organizations because conflict has an influence on patients (Forte 1997). Therefore, every attempt should be made to improve conflict management within wards. An appropriate environment (time, space and will to resolve problems) should be created that supports conflict resolution.

A second condition to resolving conflict refers to the capacity to resolve (Tidwell 1998). Possession of skills and resources is essential to manage conflict. The emergent group of nurse managers appears to be essential to the management of conflict within nursing units (Stordeur *et al.* 2001). However, it has been shown that nurses in leadership positions do not spend sufficient time on conflict resolution (Skjorshammer 2001). One main reason of such issues might be that nurses feel that they have insufficient background to deal with conflicts, as leadership role is a new type of challenge in nursing (Broome 1990, McCloskey & Grace 1994, Willmot 1998). Taking into consideration that the role of nurse managers is essential to a cost-effective health care delivery system (Wong 1998), advanced courses on personnel management for leader nurses and nursing staff should be greatly promoted (Loo 2003).

It should be finally highlighted that although growing research on nursing management has been conducted, most of the available nursing literature has avoided investigating the causes and effects of conflict in nursing units. Therefore, wider research is needed in this area to increase knowledge in nursing management.

Conclusion

It has been seen that conflict can have both positive and negative affects. It can increase creativity but can also lead to sabotage. Thus, people should first analyse which type of conflict they have to deal with. Besides, they need to identify which conflict management strategy they will use: competition, avoidance, accommodation, compromise or/and collaboration. There is no appropriate or inappropriate strategy to deal with conflict. Time availability, context, culture and type of personality should be taken into account to resolve conflict.

Nurses in wards use avoidance as a primary strategy to manage conflict. However, although on occasions this approach seems appropriate because it gives time to analyse the problem, it hinders recognition that a problem exists. Consequently, there is no active resolution of the conflict. Three central concerns have to do with explaining why nurses use avoidance as the main approach to conflict management. First, nurses still behave under the historical sequelae of the traditional paradigm of doctor dominance and nurse deference. Secondly, nurses have little time to discuss problems, as they are usually busy. This lack of time hinders communication and addressing of conflicts. Finally, nurse managers have little knowledge in conflict management, as the role of leadership is a new type of challenge in nursing that needs greater study and practice.

Further courses on conflict and personnel management should be therefore available for leader nurses. In addition, improvements in material and human conditions (time, space, nursing staff and motivation) should be greatly considered. Moreover, as there are few courses available on conflict resolution for nursing staff, it is thought that providing basic education on this matter would empower nurses to use the acquired skills in pursuit of early conflict resolution. This would subsequently have a great influence on nursing health care.

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Long-term cancer survivors: 'Who is there to work with these people?'

In response to the May Editorial 'Surviving cancer' (Editorial 2005):

Although survivors are disease-free, they may experience information and emotional needs in their long-term survivorship (Vivar & McQueen 2005). Psychosocial costs of having cancer have been shown to contribute to poorer health outcomes in long-term cancer survivors compared to individuals without cancer. Awareness on cancer survivors' quality of life therefore should be a high priority for cancer services when considering increasing survival rates.

Recently, cancer research has drawn attention on the relationship between psychological distress and survival. Despite the fact that evidence is inconclusive on this association, psychological sequel such as anxiety related to fear of recurrence is certainly a cause of preoccupation for survivors and their family members (Lee-Jones *et al.* 1997). Any minor symptom experienced seems awakening thoughts of a recurrence of cancer. The fear that cancer comes back persists over many years although remaining disease-free. Despite wide recognition of this worry among members of the multidisciplinary cancer team, survivors have still emotional and information needs that are unmet by cancer services (Vivar & McQueen 2005). These needs should be addressed in periodic surveillance by medical oncologists. Dissatisfaction in routine follow-up visits, however, has been reported by survivors. This may be because routine follow-up in our current health services are largely based on detecting recurrent disease. Consultations are generally brief and few opportunities are available to meet the survivors' psychological sequel. Unresolved concerns, however, may result in high levels of distress that could translate into poorer quality of life in long-term cancer survivors.

Nurse specialists, together with others members of the oncology team, can take an active role in the effective management of cancer survivorship (MacBride & Whyte 1998). Recommendations that promote long-term quality of life of both survivors and family members can be made in regard to the development of trained follow-up nurse

specialist facilitating open communication, giving reassurance, and providing long-term survivorship-related information. Randomised studies assessing the impact of nurse led follow-up in the management of cancer patients have reported positive outcomes in relation to efficacy, satisfaction and cost effectiveness. No research, however, has been found on the impact of nurse led follow-up in long-term cancer survivors, this probably meaning that this role has so far not been extended to routine follow-up. Cancer nurse specialist appears an ideal candidate to meet some of the special needs of long-term cancer survivors in primary care within the community. Yet, there is a lack of evidence on the impact of nurse led follow-up on quality of life of long-term cancer survivors. Therefore, it would appear that randomised research is greatly needed to assess the value and cost effectiveness of a nurse specialist who would provide supportive care in the long term survival of cancer within primary health care services. Positive results of empirical investigation can place a significant demand on policy initiatives to develop the profile of a specific nursing role that address long-term survivors' needs.

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The Editor welcomes correspondence and debate.

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